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CURRENT OPINION

Modelling Spillover Effects on Informal Carers: The Carer QALY Trap

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Abstract

The provision of informal (unpaid) care can impose significant 'spillover effects' on carers, and accounting for these effects is consistent with the efficiency and equity objectives of health technology assessment (HTA). Inclusion of these effects in health economic models, particularly carer health-related quality of life (QOL), can have a substantial impact on net quality-adjusted life year (QALY) gains and the relative cost effectiveness of new technologies. Typically, consideration of spillover effects improves the value of a technology, but in some circumstances, consideration of spillover effects can lead to situations whereby life-extending treatments for patients may be considered cost ineffective due to their impact on carer QOL. In this piece we revisit the classic 'QALY trap' and introduce an analogous 'carer QALY trap' which may have practical implications for economic evaluations where the inclusion of carer QOL reduces incremental QALY gains. Such results may align with a strict QALY-maximisation rule, however we consider the extent to which this principle may be at odds with the preferences of carers themselves (and possibly society more broadly), potentially leading decision makers into the carer QALY trap as a result. We subsequently reflect on potential solutions, highlighting the important (albeit limited) role that deliberation has to play in HTA.

1 Introduction

Ill health often affects individuals that patients are close to, especially when these individuals are providing informal (unpaid) care to the patient. Impacts can include out-of-pocket costs, loss of time, lost productivity, and quality of life impacts [1]. These so-called 'spillover effects' can be substantial and often affect multiple individuals [2, 3]; therefore, it has been argued that they should be considered when evaluating the cost effectiveness of new treatments [4, 5].

Accordingly, some health technology assessment (HTA) agencies allow for the health-related quality of life (hereafter referred to as simply 'QOL') of informal carers to be included in economic models under certain circumstances [6]. The inclusion of carer QOL usually increases net incremental quality-adjusted life year (QALY) gains, reducing incremental cost-effectiveness ratios (ICERs) and improving treatment cost effectiveness [6–9]. However, in cases where the opposite occurs, an ethical dilemma may arise. This commentary describes this ethical dilemma by first setting out the classic 'QALY trap' and introducing an analogous 'carer QALY trap'.

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Key Points for Decision Makers

Consideration of spillover effects in the economic evaluation of new technologies, such as the potential impact on the health-related quality of life (QOL) of (informal) carers, is important to consider for equity and efficiency reasons. However, whilst consideration of carer QOL often increases net quality-adjusted life year (QALY) gains, this is not always the case.

Some life-extending treatments may appear less cost effective when carer QOL is taken into consideration. If treatments are deemed cost ineffective due—at least in part—to the impact on carers, this may create an ethical dilemma for decision makers.

This commentary reflects on how carers, society, and decision makers may view and react to these situations and introduces the concept of the 'carer QALY trap', which is analogous to the classic 'QALY trap'.

We then go on to discuss the extent to which the latter may be an issue and how it could be avoided.

2 The 'QALY Trap' and the 'Carer QALY Trap'

The classic QALY trap was introduced by Ubel et al. [10]. They state that, under the principle of QALY maximisation, extending the life of a person with a chronic disease is less valuable than extending the life of a person without one, *ceteris paribus*. For example, whereas extending the life of a person in 'full health' (utility = 1.0) by one year generates one QALY, extending the life of a person with a chronic disease (say, utility = 0.3) generates less—in this example, only 0.3 QALYs for the same survival gain. If, to avoid this uncomfortable conclusion, decision makers choose to assign equal value to all lives, it would not be possible to value a cure for the chronic disease independent of the life extension, because they have chosen to disregard QOL, and therefore no value would be attributed to reducing morbidity [11]. In this situation, "the QALY model has us trapped" [10]; decision makers can either value both survival gains equally, or they can value a cure for the chronic condition, but not both.

A similar trap can be seen in the context of patients with informal carers. If providing informal care has an overall negative impact on carer QOL, then under QALY maximisation, extending the life of a patient with a carer is less valuable than extending the life of a patient without one, *ceteris paribus*. For example, imagine that as a result of providing informal care, a carer's utility is slightly lower than that of a similar (e.g., age/sex matched) person from the general population (say, 0.1 lower—a disutility of 0.1). Together, extending the life of a person with a chronic disease at a utility of 0.3, who has an informal carer with a disutility of 0.1, by one year generates 0.2 QALYs (0.3–0.1 QALYs). Without a carer, this same life extension would generate 0.3 QALYs. This leads us into a similar trap: decision makers can choose to value life extensions with or without a carer equally, or to value a reduction in the burden on informal carers, but not both. Again, the QALY model has us trapped.

3 Implications for Economic Evaluation

At the individual economic evaluation level, the classic QALY trap is not typically a problem, as the relevant comparisons are made between treatments for patients with the same health issue. However, the same cannot be said for the carer QALY trap. Patients in all arms of the analysis will have the same health issue, and the impact on informal carers should be considered in all arms. Nonetheless, it is possible for an effective treatment that provides survival gains (with relatively little or no QOL gain) to appear less effective than the comparators when carer QOL is considered, potentially giving rise to the carer QALY trap. We describe such scenarios in Table 1.

In both examples, a new treatment offers a life extension of one year relative to the comparator but does not improve patient QOL. In example A, relative to the comparator, the new treatment increases lifetime patient QALYs by 0.25. Accounting for carer QOL, however, reduces the (net) QALYs for both treatments, decreasing the incremental QALY gain offered by the new treatment by 20% to 0.20 QALYs. In example B, relative to the comparator, the new treatment offers an incremental QALY gain for patients of 0.05 QALYs. Capturing carer QOL reduces the (net) QALYs such that both treatments result in net QALY *losses*, with the new treatment providing an incremental loss of 0.05 QALYs despite the fact that no individual is in a health state that is considered to be worse than dead. In this case, the new treatment would not be cost effective at zero price, and—under strict QALY maximisation—societal value would be maximised by the earlier death of the patient.

The issue in these examples is not the calculations. The negative impact on carers' QOL has been extended and therefore the new treatments do not maximise potential QALYs. However, an ethical dilemma may arise if carers (or society more broadly) disagree with the implication that—*on the basis of the carer's loss of QALYs*—life-extending treatments for the patient should not be funded. If, as discussed earlier, decision makers address this potential disconnect

Table 1 Hypothetical examples whereby consideration of carer QOL reduces QALY gains

	Standard of care	New treatment	Incremental change
Example A			
Life years	1	2	+ 1 year
Patient utility	0.25	0.25	0
Patient QALYs	0.25	0.5	+ 0.25 QALYs
Carer disutility	0.05	0.05	0
(Patient utility) – (carer disutility)	0.20	0.20	0
Net QALYs	0.20	0.40	+ 0.20 QALYs
Example B			
Life years	1	2	+ 1 year
Patient utility	0.05	0.05	0
Patient QALYs	0.05	0.10	+ 0.05 QALYs
Carer disutility	0.10	0.10	0
(Patient utility) – (carer disutility)	– 0.05	– 0.05	0
Net QALYs	– 0.05	– 0.10	– 0.05 QALYs

QALY quality-adjusted life-year, *QOL* health-related quality of life

between QALY maximisation and carer/societal preferences by disregarding carer QOL impacts, then we find ourselves in the carer QALY trap.

These are not strictly theoretical concerns. In two recent National Institute for Health and Care Excellence (NICE) technology appraisals (TA588 and TA755), the inclusion of carer QOL in the economic models resulted in fewer QALYs being accrued with the new treatment, contributing to the treatment being deemed not cost effective [12, 13]. The implication was that life-extending treatments may not represent an efficient use of resources, at least in part due to the negative QALY impact that they would have on informal carers. Given that the treatments were for type 1 spinal muscular atrophy, which affects infants, with informal care typically provided by parents, it is not surprising that the model output and the implication that an earlier death of the infant would maximise carer QOL was considered "perverse" by patient experts [12].

4 Is This a Problem?

The inclusion of carer QOL in economic models resulting in fewer (net) QALYs being accrued may be a relatively uncommon occurrence in practice. It is more likely to occur when treatments offer a life extension but little in the way of a QOL improvement for patients (as this subsequently improves carer QOL). For a net QALY loss to occur, it is necessary for the carer disutility to exceed the patient's utility for a substantial portion of the time horizon of the model, which requires a combination of very poor patient QOL and very high carer disutility that may be rare but, as we have seen, not impossible.

Whether this is an issue ultimately boils down to whether people agree or disagree with the implication that life-extending treatments should not be funded if their impact on carers is substantial enough to outweigh patient QALY gains. Carers may assign a value to a new treatment that reflects not only (or even primarily) the impact on their own QOL [14]. From this perspective, it seems to us unlikely that carers would agree that life-extending treatment should be denied out of concern for their QOL. Carers will, of course, value improvements in their own QOL, but not necessarily if this comes at the expense of the survival of the person for whom they are caring.

An additional question is how societal preferences should be considered in this context. One plausible but uncomfortable possibility is that societal concern for carer QOL could outweigh carers' own concern, and therefore recommend against life-extending treatments that carers themselves would prefer. This is somewhat analogous to the 'patient versus public' debate in health state valuation, where society may undervalue certain health states from the perspective of patients [15]. The relative social value of carer QOL compared with patient QOL has been explored recently [16], but little is known about how this may vary in different contexts, and what the implications may be for HTA.

5 If the Carer QALY Trap is a Problem, What Could Be Done?

In terms of the economic models themselves, as the model output is not incorrect, there is arguably no need for a technical 'fix'. Nonetheless, when this issue does occur, it is important to consider how, if at all, it should be dealt with in practice. If decision makers opt to ignore results that account for carer QOL, they would find themselves in the carer QALY trap, and therefore we argue that this not the correct approach. As a result, in the first instance, it is important that those involved in HTA decisions are aware that consideration of carer QOL may reduce overall (net) QALYs, and that they understand the circumstances in which this is likely to occur, as well as the potential implications of ignoring it. Given that HTA decisions do not strictly follow a QALY-maximisation rule and instead rely on deliberations *informed* by a quantitative model, a pragmatic solution to this issue would be to consider the impact on carer QOL through deliberation. To inform these deliberations, analysts should present a range of scenario analyses (with and without carer QOL, and varying any relevant assumptions), and it may be useful if disaggregated results are also presented. Furthermore, alternative measures of value developed to address the classic QALY trap, such as equal value of life-years [17, 18] or healthy years in total [19], may be a useful supplement for illustrating the value of life extension whilst also allowing independent consideration of QOL impacts. Deliberations could also be supplemented with carer testimonials and data on the carer burden collected using rigorous qualitative and/or quantitative scientific methods. However, it is important to keep in mind that deliberation has its limitations. Deviating from the QALY-maximisation rule and recommending interventions that would not normally be considered cost effective will have implications in terms of opportunity costs and health losses for other, unidentified groups.

More broadly, it is also worth noting that better measurement of carer QOL may reduce the likelihood of negative (net) QALYs being accrued when carer QOL is included in models in the first place. As noted by Pennington [8], carer QOL data should be derived from longitudinal studies. Such data, however, are rarely collected. Longitudinal data, particularly carer QOL data collected alongside clinical trials, may better capture the *benefits* of new treatments for carers that are not derived directly from improvements in patient QOL. Additionally, the inclusion of bereavement effects (the negative QOL impact—or disutility—experienced by carers following the death of the patient) may offset carer QALY losses that occur with treatments that extend survival to some extent. This is because the impact of bereavement is reduced when survival is extended, as the bereavement occurs later and is therefore more heavily discounted in the model. However, the incremental impact may be small if the magnitude of the disutility does not differ between arms. Ultimately, relatively little is known about bereavement effects and methods to estimate them are not well developed, as noted by NICE in their recent methods review [20]. As such, their inclusion in economic models is contentious at present. Finally, there is also arguably a broader measurement question that relates to whether the consideration of QOL alone is too narrow in this context, and whether process utility [21] and/or broader constructs such as wellbeing should be considered to capture the potential positive impacts of providing informal care (which may, in turn, offset the negative impacts).

6 Concluding Remarks

For certain groups of patients, life-extending treatments may appear less effective when carer QOL is considered and, therefore, may be less likely to be funded. This is not an error in the application of the QALY framework, nor is it a modelling error, and therefore there is arguably no need for a technical 'fix' or indeed any substantive changes to typical HTA processes.

However, we believe that it is plausible that carers, and perhaps even the public, would disagree with the implications of such results. Such a divergence would imply that the QALY-maximisation rule fails to reflect the values of carers and wider society. Indeed, there is an irony that these "perverse" results are driven by a concern for carers' QOL that the carers themselves may not share. Further research is needed to understand the views of carers and society in this context.

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