Delayed Effect Approach to Resolve the Carer QALY Trap

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BACKGROUND & OBJECTIVES

Caregiver spillover effects are increasingly recognized as relevant in health economic evaluation. However, existing approaches may generate substantially different conclusions depending on how caregiver outcomes are modeled. The utility approach tends to produce large positive caregiver gains because caregiver utility is accumulated over the full survival period. In contrast, the disutility approach may produce negative caregiver outcomes when patient survival is prolonged, because caregiving burden is assumed to continue for longer. This phenomenon has been described as the carer QALY trap.

The increments approach partially addresses this problem by focusing on differences relative to a baseline state rather than accumulating absolute caregiver utility. However, its interpretation depends strongly on the choice of baseline, and it does not directly capture the benefit of delaying transition to a more severe disease state.

To address this limitation, we propose a “Delay Effect Approach” or “Delayed Deterioration Approach (DDA). This approach estimates caregiver benefit as the quality-adjusted life years preserved by delaying patient progression from a less severe state to a more severe state. Rather than valuing all caregiving time, DDA values the avoidance of deterioration-related caregiver quality of life loss.

METHODS

Conceptual framework

The proposed approach builds on the logic of the increments approach but redefines the reference state. Instead of comparing caregiver utility with a general baseline such as death, no-care, or population norm, DDA compares the observed caregiver quality of life under delayed deterioration with the counterfactual caregiver quality of life that would have occurred had the patient already progressed to a severe state. Thus, caregiver benefit is defined as the avoided deterioration-associated decrement in caregiver quality of life.

Formula

For a time period in which deterioration is delayed, caregiver gain is defined as:

$$\Delta QALY_{DDA}^{carer} = \sum_{t=1}^{T} (U_{non-severe,t}^{carer} - U_{severe,t}^{carer})$$

If utility values are assumed constant within the delayed period, this simplifies to:

$$\Delta QALY_{DDA}^{carer} = (U_{non-severe,t}^{carer} - U_{severe,t}^{carer}) \times T_{delay}$$

where:

- $U_{non-severe}^{carer}$: caregiver utility while the patient remains in the less severe state
- U_{severe}^{carer} : caregiver utility after patient progression to severe disease
- T_{delay}: duration of delayed deterioration

Illustrative example

We assumed the following caregiver utility values:

- Caregiver utility while patient remains non-severe: 0.82
- Caregiver utility after progression to severe disease: 0.70
- Delay in severe progression: 2 years

Therefore:

$(0.82-0.70) \times 2 = 0.24$ The estimated caregiver gain is 0.24 QALYs.

Positioning relative to existing approaches

The proposed method is not intended to estimate the caregiver’s total lifetime QALYs. Rather, it estimates the incremental caregiver gain attributable to delayed deterioration. Therefore, it is best understood as a state-transition, counterfactual increment method focused on avoided decline.

Conflicts of Interest: The authors declare no conflicts of interest.

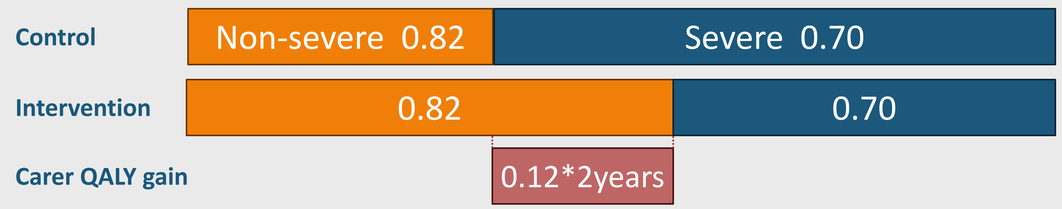
RESULTS

Conceptual findings

Using the illustrative example, the Delayed Deterioration Approach generated a caregiver gain of 0.24 QALYs over a 2-year delay in progression to severe disease.

This estimate reflects the preservation of caregiver quality of life that would otherwise have been lost if severe disease had occurred earlier. Unlike the disutility approach, the proposed method does not automatically penalize an intervention simply because the patient lives longer. Instead, it captures the caregiver benefit of remaining in a less burdensome disease state for longer.

Figure 1. Conceptual structure of the Delayed Deterioration Approach



Interpretation

The main conceptual result is that DDA avoids the carer QALY trap by restricting estimation to avoided deterioration-related loss rather than total caregiving time. This makes the measure more directly aligned with interventions whose principal benefit is to delay disease progression rather than eliminate care needs altogether.

Under the same hypothetical scenario, different approaches would be expected to behave differently. Table 1 compares existing approaches.

Table 1. Comparison of caregiver modeling approaches

Approach	Core idea	Likely implication
Utility approach	Accumulates absolute caregiver utility over time	May overestimate positive caregiver effects
Disutility approach	Accumulates caregiver burden over time	May generate negative caregiver gains with prolonged survival
Increments approach	Uses differences from a baseline state	Sensitive to baseline choice
Delayed Deterioration Approach	Values avoided caregiver utility loss due to delayed severe progression	Focuses on progression-related caregiver benefit and may avoid carer QALY trap

DISCUSSION & CONCLUSIONS

- The Delayed Deterioration Approach offers a pragmatic extension of the increments approach for settings in which the main clinical effect of treatment is to delay worsening disease severity. Its main strength is that it produces an intuitively interpretable caregiver benefit: the amount of caregiver quality of life preserved while severe deterioration is postponed.
- This approach may be particularly useful in chronic progressive diseases in which transition to severe disease substantially increases informal caregiving burden. In such settings, DDA may better reflect the value of treatment than approaches that either sum all caregiver utility or treat longer survival as longer burden.
- However, several limitations should be acknowledged. First, DDA does not estimate the full caregiver spillover effect. It captures only the benefit associated with delayed deterioration. Second, the method depends on a counterfactual assumption about what caregiver utility would have been under earlier severe progression. Third, DDA does not separately identify emotional family effects and caregiving burden effects. Therefore, it should be interpreted as a focused incremental method rather than a comprehensive caregiver outcome framework.
- Despite these limitations, DDA may be useful as a transparent and policy-relevant method when the objective is to estimate caregiver gains associated with delaying severe disease progression while avoiding the negative bias implied by the carer QALY trap.