

CAREGIVER QALYS DESERVE BETTER: WHY IT'S TIME FOR A METHODOLOGICAL RETHINK

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Introduction

- Including caregiver quality adjusted life years (QALYs) in economic evaluations is becoming more common, but the methods used to do so differ widely.
- This study compares these methods across a range of interventions, showing how different approaches can lead to very different results, and why a clearer, more consistent framework is needed.

Objective: To show how different approaches to modelling caregiver QALYs can lead to very different results, and why a clearer, more consistent framework is needed

Methods

- We developed a hypothetical model with five health states: cure, mild, moderate, and severe disease, plus death (Figure 1).
- The model estimated patient life years spent in each health state under standard of care (SOC) and six intervention scenarios, representing different combinations of cure, morbidity reduction, and survival benefit (Table 1).
- We applied six approaches used in prior studies to incorporate caregiver QALYs:
 - Caregiver utilities** – using absolute utility values.
 - Caregiver disutilities** – capturing loss relative to baseline.
 - Disutilities relative to the best health state** – capturing loss relative to the best health state.
 - Increments relative to the worst health state** – capturing benefit relative to the worst health state.
 - Disutilities/increments from a midpoint health state** – capturing loss or benefit relative to the midway health state i.e., moderate disease.
 - Included for patient cure and death health states
 - Excluded for patient cure and included for patient death health states
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 - Proportional/multiplier approach** – linking caregiver effects to patient outcomes.
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- Incremental caregiver QALYs were estimated from the total QALYs for each intervention relative to SOC.

Results

- Figure 2 compares the incremental caregiver QALYs generated by each methodological approach across all SOC vs. intervention comparisons.
- Except for the proportional/multiplier approach, results align for non-curative interventions (1–4) with consistent death assumptions. For intervention (5), alignment occurs only when including caregiver impact in the cured state, and for intervention (6), only when including impacts in both cured and death states.

Figure 1: Hypothetical Model Structure

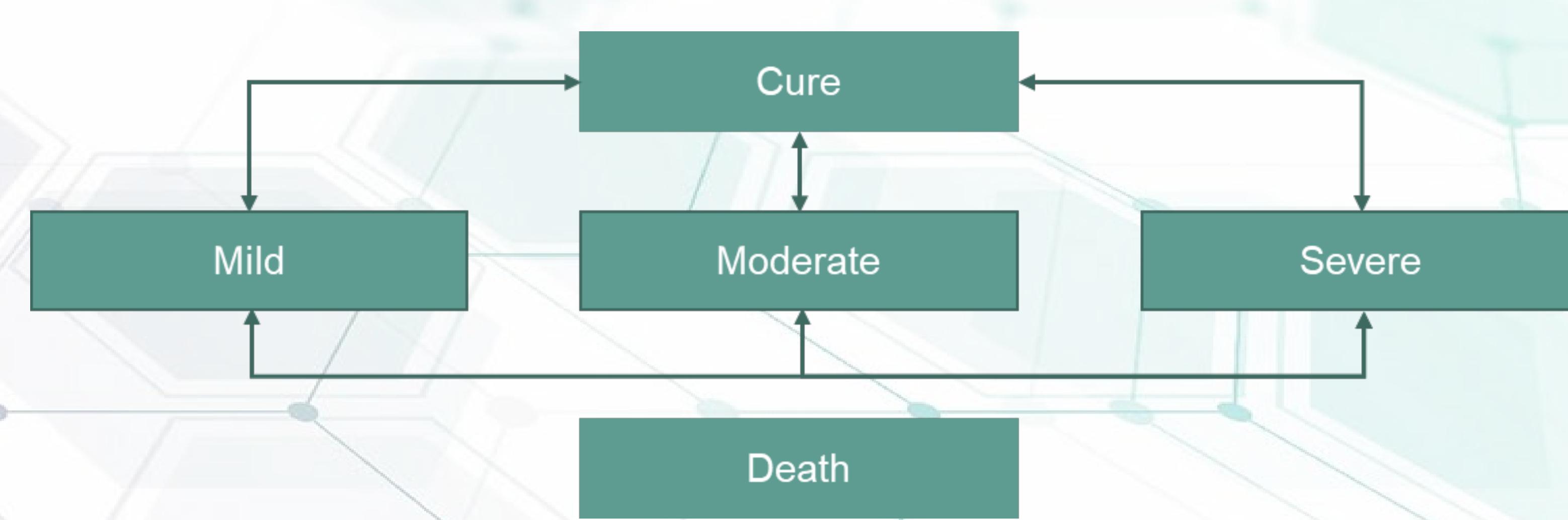


Table 1: Estimated Patient Life Years

Health states	SOC	Intervention					
		1. Treatment improves morbidity but does not impact survival	2. Treatment extends survival in all states	3. Treatment extends survival only in best state	4. Treatment extends survival only in worst state	5. Treatment cures patients but does not affect survival	6. Treatment cures patients and improves survival
Cure	0	0	0	0	0	9	15
Mild	3	7	5	9	3	0	0
Moderate	3	1	5	3	3	0	0
Severe	3	1	5	3	9	0	0
Death	6	6	0	0	0	6	0
Total	15	15	15	15	15	15	15

Figure 2: A Comparison of Incremental Caregiver QALYs Across Different Approaches

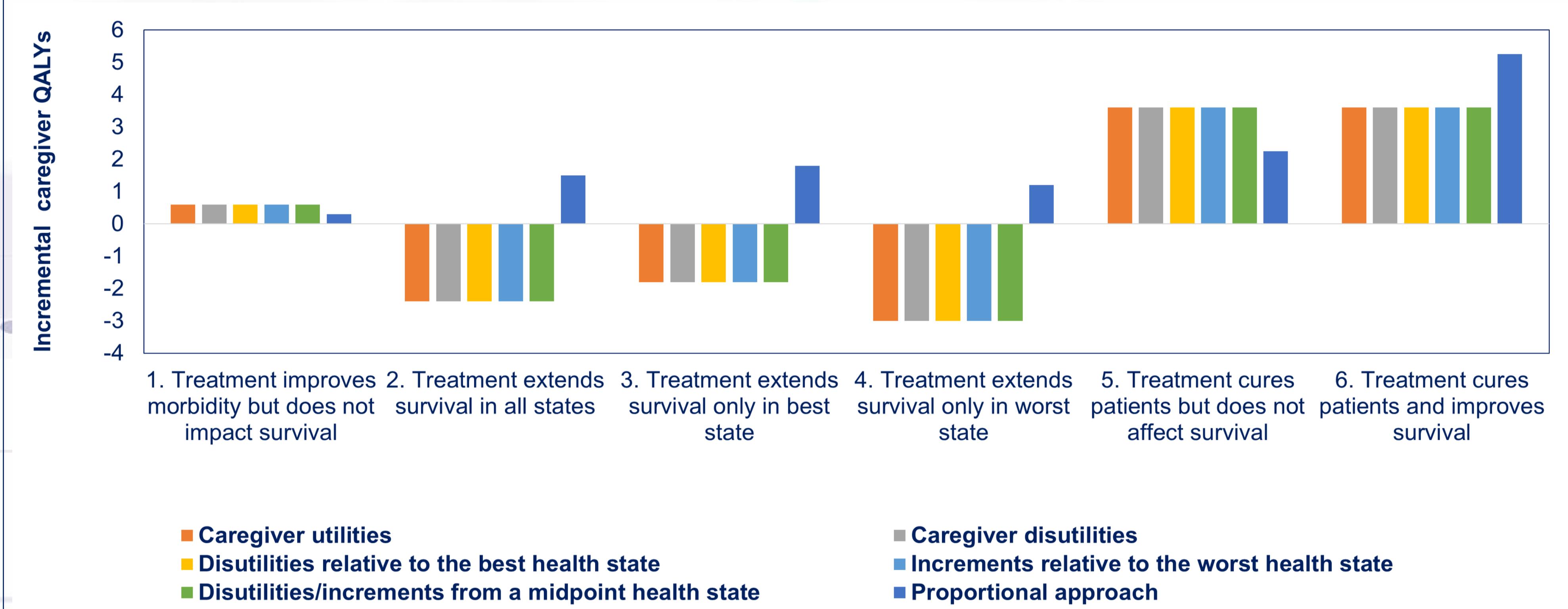


Figure 3: Inclusion/exclusion of cure

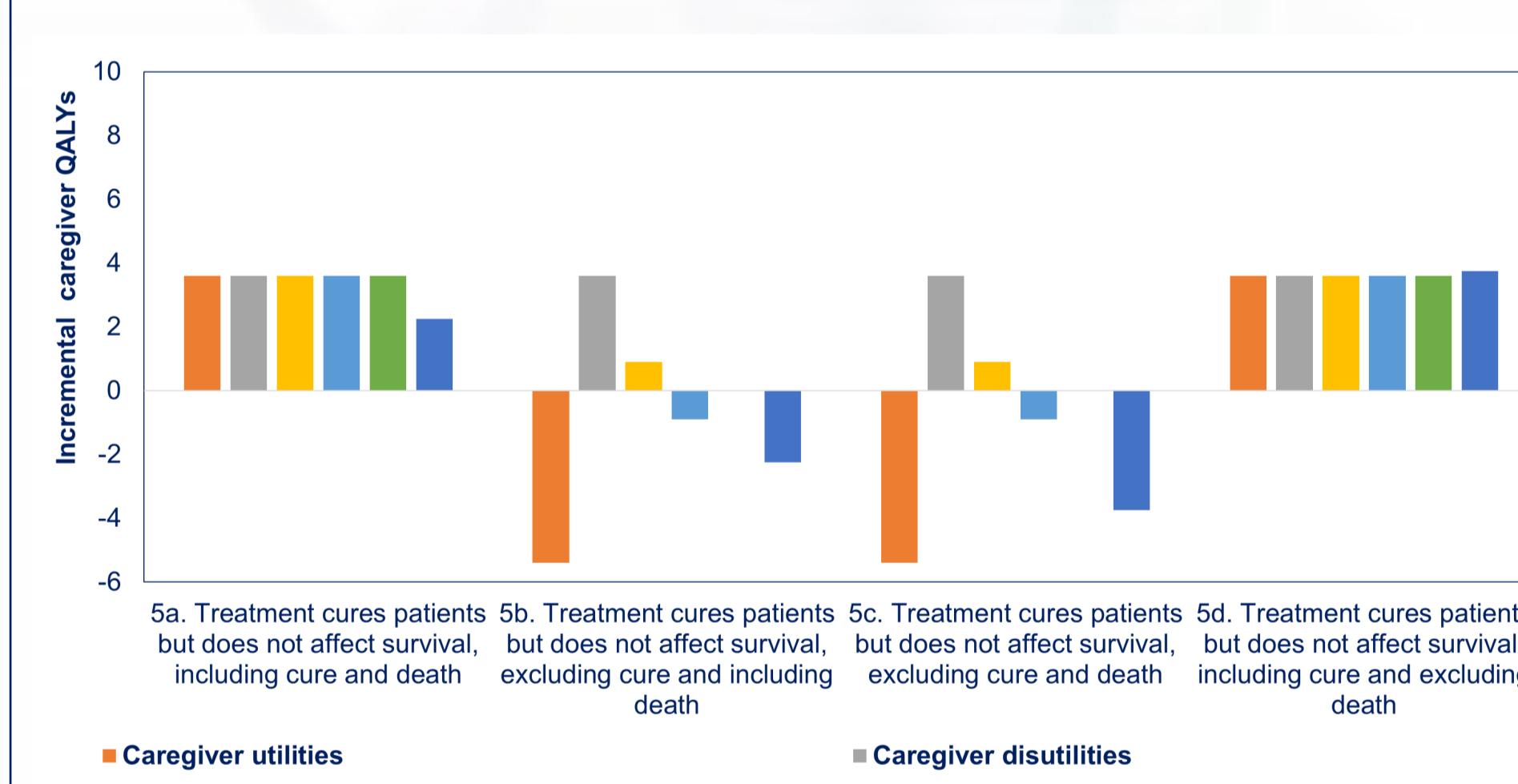
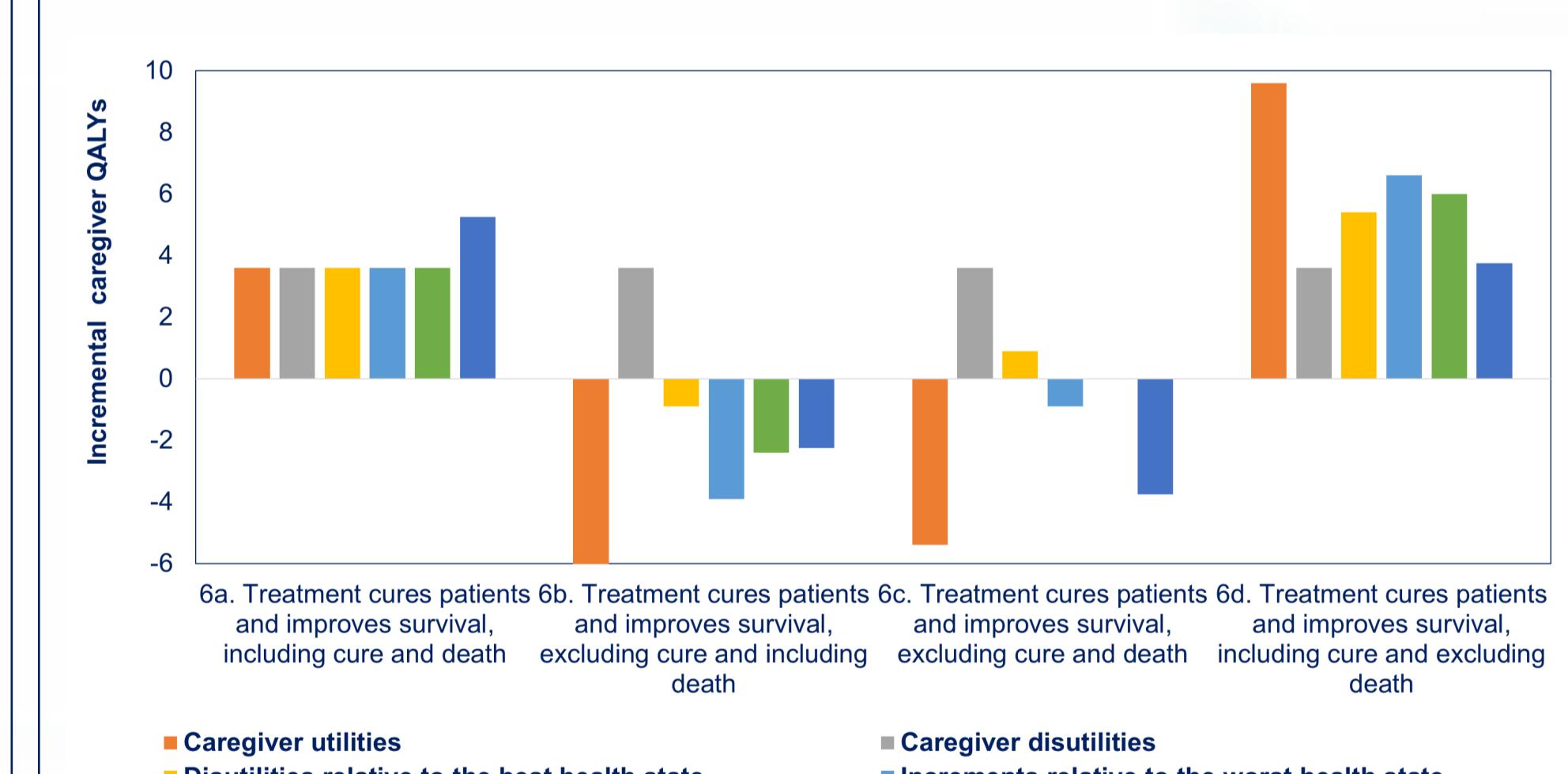


Figure 4: Inclusion/exclusion of cure and death



Results continued

- The proportional/multiplier approach results in consistently positive incremental caregiver QALYs across all SOC vs. intervention comparisons.
- For hypothetical intervention (5) i.e., treatment cures patients but does not affect survival, results diverge based on the exclusion of impact of patient cure on caregivers' QALYs (Figure 3).
- For hypothetical intervention (6) i.e., treatment cures patients and improves survival, results diverge based on the exclusion of impact of patient cure and death on caregivers' QALYs (Figure 4).

Conclusion

- Methods align for caregiver QALYs during active disease but diverge after patient cure or death. Caregiver impacts may persist beyond cure or death, reflecting emotional and social effects. Assuming an immediate return to population norms oversimplifies real-world experience.
- We must distinguish between the burden of caregiving and the impact of caring.
- A consistent, equitable approach is needed for modelling caregiver QALYs. Future work should involve economists, policymakers, clinicians, and caregivers alike.

Abbreviations: QALY, quality adjusted life year; SOC, standard of care.

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