



The Carer QALY Trap and Altruism in Economic Evaluations

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The idea that carer quality-adjusted life-years (QALYs) should be included as a measure of outcome valuation for patient interventions to treat or prevent health conditions, is now widely accepted in economic evaluation involving child health services. It simply is not possible to disentangle health impacts on children arising from serious conditions from the impact on the parents (carers) [1]. That the “evaluative scope” in an economic analysis should be broadened to include carers in adult populations with their subsequent distributional consequences and normative implications [2], is advocated for in evaluations using a societal perspective [3], and recommended by health technology agencies in the USA and UK [4, 5], but not widely employed [6]. Despite the general acknowledgement of the importance of including carer QALY spillover effects in economic evaluations, guidance on measuring spillover effects from patients to carer is lacking, especially in cases where interventions create survival gains.

The problem of how to incorporate spillover effects in economic evaluations becomes evident in the report by Mott et al. in this issue of *Pharmacoeconomics* [7]. As they describe it, an intervention can lead to survival gains where the quality of life (QoL) of the patient is low leading to minimal QALY gains, yet the low QoL for the patient can cause carers to lose QALYs with a greater loss, leading to an overall negative loss in total QALYs. Under a QALY maximization rule, the negative QALYs due to carer spillover effects leads to the conclusion that the intervention should **not** be adopted even though it extends life for the patient. Mott et al.

describe this phenomenon as “The carer QALY trap” following the well-known QALY trap involving patients [8, 9]. The headline story in their article includes two real-world examples of the carer QALY trap playing out in National Institute for Health and Care Excellence reviews for the treatment of spinal muscular atrophy where treatment was found not cost effective [10, 11]; findings deemed “perverse” by patient experts.

Giving credit where credit is due, Mott et al. add to the literature by thinking through the ramifications of the carer QALY trap and by coining a phrase that can be used to describe the problem at hand. However, the problem is not new. Lundin and Ramsberg described the same problem with a parable in the context of survival consumption costs [12]. In brief, Lundin and Ramsberg portray two people on an island needing to decide whether to create a snake bite antidote that would save the life of the person after being bitten. The island snakes resided in an area with better food, and picking fruit there would increase the QoL of the two inhabitants on the island but incur the risk of being bitten while picking fruit. If one person is bitten and survives using the antidote, in the parable by Lundin and Ramsberg, the survivor would live with a very low QoL. The healthy person would then incur survivor consumption costs by having to provide for the person who survived the snake bite. The link to the carer QALY trap is straightforward; in providing for the person with the snake bite, the healthy person loses QALYs. Importantly, altruism is not considered in their parable.

In the end, Lundin and Ramsberg suggest “if the quality of life for the person who survived was very low, and if the healthy person’s disutility from the extra hours of work was very high, the right decision could be not to treat.” (p. 295) They then ask the relevant question “why should a person work so hard in the coming years if it is not much use for the other person anyway?” (p. 295)

To answer their question with a question, what if the two people on the island are twins (or a married couple for example) who could not imagine a life without each other? Adding altruism to the story leads to a different conclusion and

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points to the need for an evaluation that considers the siblings QALYs lost from losing their twin or QALYs gained in the case of survival. Despite the need for including QALYs in this scenario, the field simply does not have a solution. Including only the QALYs of the carer in their current state (without the QALYs gained or lost from the death or survival of the twin) misrepresents the evaluative scope.

One of us (JMT) faced this problem when evaluating whether more aggressive treatment for pediatric traumatic brain injuries was a good idea. At the time, clinicians frequently commented that they could save more children with severe brain injuries, but the outcome (both for the patient and the carer) would not be worth it. The research team thus naively set out to measure QALYs in children who survived a severe brain injury as well as their caregivers. It became clear during the evaluation that measuring QALYs of the carers is problematic because of bias and not the correct scope anyway. For example, one carer noted that his child suffered a severe brain injury, the child was also paralyzed, and his spouse died in the crash. He asked if we still wanted to interview him. Clearly, direct measurement of carer QALYs in this case was confounded by unobserved events and the disutility that would be measured would be against unaffected carers, when the correct scope requires a comparison between affected carers and carers that lost their child in the crash.

Would the carer prefer the child's current brain-injured state to a state of death? Would the carers be willing to pay for the outcome that was achieved or more importantly, would a representative sample of the population be willing to pay for the (average) outcome? It turned out the QALYs of children with severe brain injuries were sufficient to argue that more aggressive treatment was warranted [13]. It would stretch the imagination to think carers or society would not be willing to pay for the outcomes that were achieved. Including the QALYs lost by carers of children with severe brain injuries relative to unaffected carers would have had a substantial impact on total QALYs and reduced the cost effectiveness of improving outcomes. Instead, clinicians heard that more aggressive treatment was worth it and this message may be partly responsible for the continued trend in improved survival of brain injured children. We believe not including QALYs of carers relative to unaffected carers without taking altruism into account was the right decision.

Mott et al. ask appropriate questions about the QALY trap including "Is this a problem?" and "if the carer QALY trap is a problem, what could be done?" To the first question, we argue the carer QALY trap is a problem with a history (but not a cool title). Carers and society in general have dealt with the QALY trap absent the title. Parents face the decision as to whether a child with significant birth defects should be carried to term with both the QoL of the child and the QoL of the parents factoring into the decision. In cases where a

major congenital fetal abnormality is detected, the majority end in termination for medical reasons [14]. In the USA, approximately 4% of abortions stem from maternal life or health being at risk [15]. Unfortunately, the new environment in US abortion policy may lead to forced deliveries that go against the preferences of the parents and clinical evidence in general while causing harmful outcomes to the mother. What should we call this scenario, a holy hell trap?

In the case of less clear-cut decisions, Mott et al. speak to the difficult question of whether society should recommend a decision not to treat when the carer values the patient QoL more than the loss in their own QoL. We would argue that the carer (and the larger society) may value low patient QoL outcomes because of altruism, a concern likely not captured in the National Institute for Health and Care Excellence examples. If health technology assessment agencies are to consider the case of society valuing carer QoL over patients, a fully informed valuation should include the potential for altruism in decision making.

As to the second question, the views above suggest the appropriate action for policy. Health technology agencies and the field lack an understanding of preferences for health states by carers regarding children or adults with very low health states relative to zero patient QALYs (death). If carers prefer, or more precisely, are willing to pay for very low health states over death, then negative QALYs are not possible (negative QALYs are a consequence of the wrong scope — evaluating the health state of the carer of a patient with low QALYs relative to unaffected carers) and the carer QALY trap is avoided. Negative QALYs can only arise in the case where carers value death over very low health states. Reading Mott et al. carefully leads us to the belief that they too believe "perverse results" should be avoided. We believe incorporating altruism into the decision-making process is a good approach to achieve correct decisions. We also recognize the potential for using outcomes other than QALYs as mentioned by Mott et al.

Lundin and Ramsburg end their essay with an appreciative note attributed to John Nyman [16]: "first understand the policy conclusions that are internally consistent with the welfare model and then examine the conclusions to determine in what way they may be inconsistent with other evidence regarding society's welfare" (Nyman, 2006, p. 319). If one believes that the welfare model is the sum of the willingness to pay of all persons affected by a program or treatment decision including altruistic concerns [17], then one has to ask how close does the carer QALY trap align with this definition? We think not close. Lundin and Ramsberg ignored altruism in their parable, and thus passed on another point by Nyman: "a more complete welfare model would specify utility so as to *account for the altruistic effect* that another's health would have on my utility" (Nyman, 2006, p. 319–20; emphasis added). Failure to include altruism

through the parent's or carer's preferences for the patient's health state with a very low QoL relative to a state of death in an economic evaluation leads to perverse results that are inconsistent with a society's welfare.

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