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Modelling Spillover Effects on Informal Carers: The 'Carer QALY Trap'

Presenting Author:

Dr David Mott

SENIOR PRINCIPAL ECONOMIST | OHE

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*Expert roundtable participant

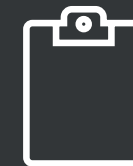
Presentation structure

- Carer quality of life and health technology assessment
- The 'carer QALY trap'
 - Overview
 - When might it occur?
 - Is it a problem?
- Why call it the 'carer QALY trap'?
- What could be done?

RESEARCH ACTIVITIES CONDUCTED



LITERATURE REVIEW



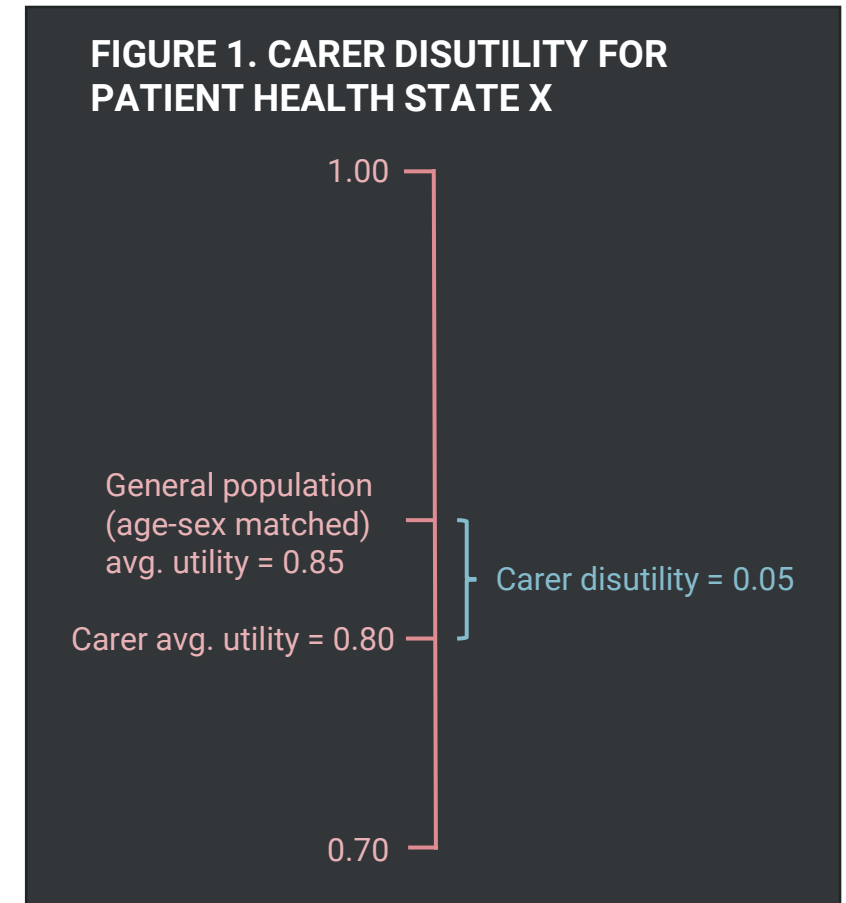
MODELLER SURVEY



EXPERT ROUNDTABLE

Carer quality of life and health technology assessment

- Ill health often affects other individuals in addition to the patient – such as informal carers – and it is important to capture such spillover effects in economic evaluations of new treatments
- Incorporating carer quality of life (QOL) into economic models is permitted by several HTA agencies, including NICE
 - However, a review of NICE appraisals by Pennington (2020) found that carer QOL has been included in relatively few appraisals
- When carer QOL is included, it is typical for carer disutilities to be used (see Figure 1) within models



The carer QALY trap: overview

- In some cases, including carer QOL in models can result in smaller incremental QALY gains

	Standard of Care
<u>Excluding carer QOL</u>	
Life years	1 year
Patient utility	0.5
Patient QALYs	0.5 QALYs

The carer QALY trap: overview

- In some cases, including carer QOL in models can result in smaller incremental QALY gains

	Standard of Care	New Treatment
<u>Excluding carer QOL</u>		
Life years	1 year	2 years
Patient utility	0.5	0.5
Patient QALYs	0.5 QALYs	1 QALY

The carer QALY trap: overview

- In some cases, including carer QOL in models can result in smaller incremental QALY gains

	Standard of Care	New Treatment	Difference
<u>Excluding carer QOL</u>			
Life years	1 year	2 years	+1 year
Patient utility	0.5	0.5	0
Patient QALYs	0.5 QALYs	1 QALY	+0.5 QALYs

The carer QALY trap: overview

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	Standard of Care	New Treatment	Difference
<u>Excluding carer QOL</u>			
Life years	1 year	2 years	+1 year
Patient utility	0.5	0.5	0
Patient QALYs	0.5 QALYs	1 QALY	+0.5 QALYs
<u>Including carer QOL</u>			
Carer disutility	0.1	0.1	0
(Patient utility) – (carer disutility)	0.4	0.4	0

The carer QALY trap: overview

- In some cases, including carer QOL in models can result in smaller incremental QALY gains

	Standard of Care	New Treatment	Difference
<u>Excluding carer QOL</u>			
Life years	1 year	2 years	+1 year
Patient utility	0.5	0.5	0
Patient QALYs	0.5 QALYs	1 QALY	+0.5 QALYs
<u>Including carer QOL</u>			
Carer disutility	0.1	0.1	0
(Patient utility) – (carer disutility)	0.4	0.4	0
Net QALYs	0.4 QALYs	0.8 QALYs	+0.4 QALYs

20% decrease

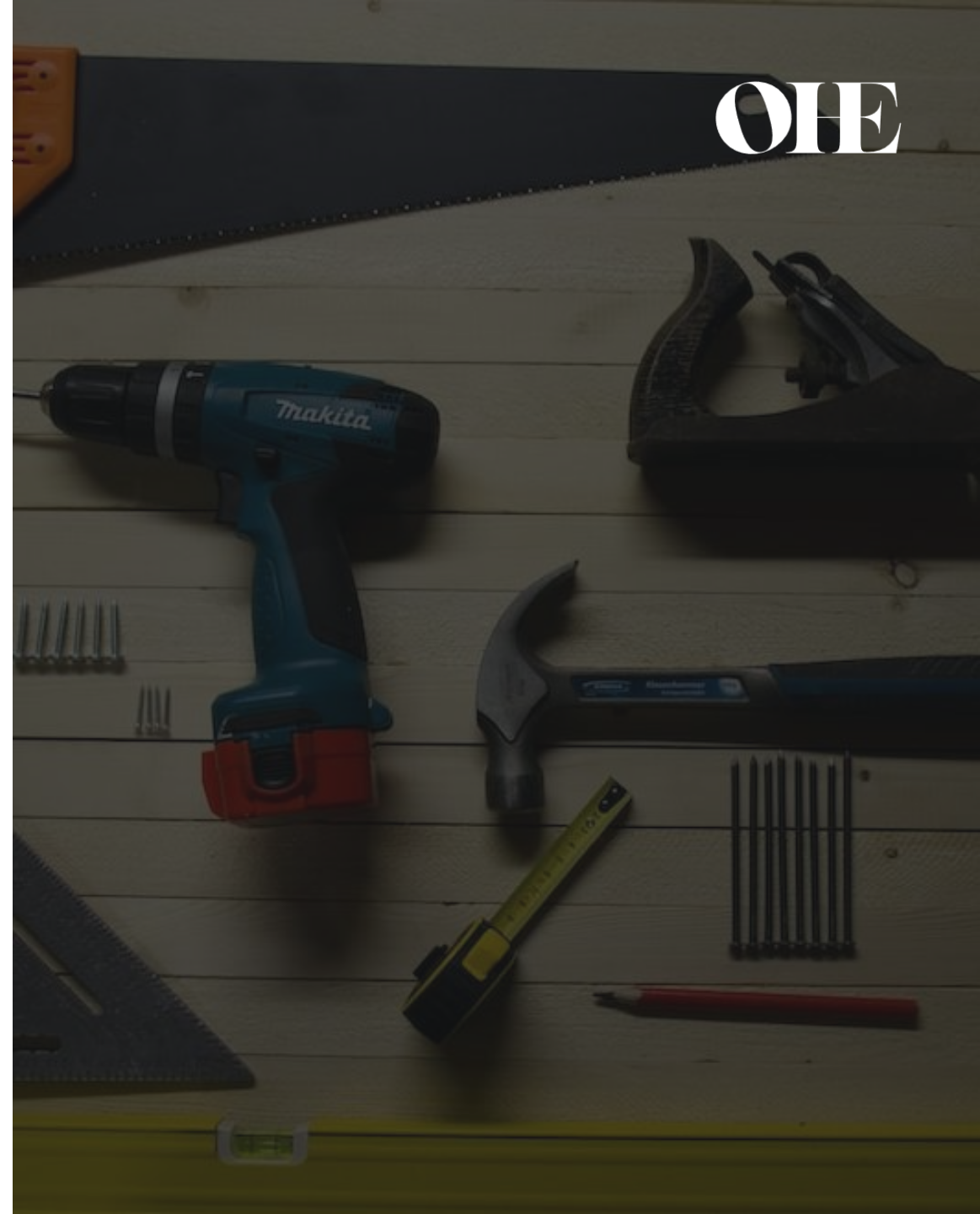
In extreme cases, the inclusion of carer QOL may lead to incremental net QALY losses

What could increase the chances of this occurring and/or its impact?



Is there actually a problem to fix?

- Treatments that extend the life of patients, without significantly improving patient QOL, ultimately extend the burden on carers without alleviating it
 - In the previous example incremental *net* QALY gains decreased – this is not an error
- However, the implications of this may be at odds with the preferences of informal carers and the general population
 - If so, this disconnect between the model and stakeholder preferences should be considered by decision making committees



Why call it the ‘carer QALY trap’?

- We see parallels between this issue and the ‘QALY trap’ introduced by Ubel et al. (2000)
 - Extending the life of a person with a chronic illness is less valuable than extending the life of a person without one, if all else is equal
 - If you disregard QOL to deal with this, then curing the chronic illness no longer has value
- In a similar vein...
 - Extending the life of a person with an informal carer is less valuable than extending the life of a person without one, if all else is equal
 - If you disregard the QOL of carers, then alleviating the carer burden no longer has value

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Improving Value Measurement in Cost-Effectiveness Analysis

PETER A. UBEL, MD,* ERIK NORD, PHD,† MARTHE GOLD, MD,‡ PAUL MENZEL, PHD,§
JOSE-LUIS PINTO PRADES, PHD,¶ AND JEFF RICHARDSON, PHD||

OBJECTIVE. Before cost-effectiveness analysis (CEA) can fulfill its promise as a tool to guide health care allocation decisions, the method of incorporating societal values into CEA may need to be improved.

DESIGN. The study design was a declarative exposition of potential fallacies in the theoretical underpinnings of CEA. Two values held by many people—preferences for giving priority to severely ill patients and preferences to avoid discrimination against people who have limited treatment potential because of disability or chronic illness—that are not currently incorporated into CEA are discussed.

CONCLUSIONS. Traditional CEA, through the measurement of quality-adjusted life years

(QALYs), is constrained because of a “QALY trap.” If, for example, saving the life of a person with paraplegia is equally valuable as saving the life of a person without paraplegia, then current QALY methods force us to conclude that curing paraplegia brings no benefit. Basing cost-effectiveness measurement on societal values rather than QALYs may allow us to better capture public rationing preferences, thereby escaping the QALY trap. CEA can accommodate a wider range of such societal values about fairness in its measurements by amending its methodology.

Key words: Cost-effectiveness analysis; quality-adjusted life-years; person tradeoff; rationing; disability; quality of life; ethics. (Med Care 2000;38:892–901)

What can be done?

- A technical modelling fix is arguably not necessary – as the models are not wrong
- Carer QOL could be excluded from models, but ultimately if the treatment does impact carer QOL, then excluding it would risk inefficient and inequitable decisions being made (Brouwer, 2019)
- Therefore, those involved in HTA decisions should be aware of the existence of the carer QALY trap and its potential implications, in order to aid their deliberations
- One way to enhance these deliberations could be to review results with alternative metrics to the QALY that disaggregate life extensions and QOL gains, such as:
 - Equal value of life approach (Nord et al., 2003)
 - Health years in total (Basu et al., 2020)
- Whether these metrics may be useful *beyond* cases where the carer QALY trap occurs is another debate

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THANK YOU!
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