

P5. QALYs and carers

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Abstract

QALY gains are starting to be estimated for unpaid carers in economic evaluations, a trend that is likely to continue in the UK following recent NICE guidance directing researchers to consider health effects on carers ‘when they are important’. This paper draws on a review of empirical and theoretical literature on unpaid care and economic evaluation to address two issues. First, how have QALYs for carers been estimated and incorporated in economic evaluation to date? Second, is it *appropriate* to use QALYs as an estimate of benefits to carers?

QALY gains for carers are invariably small and this could be due to minimal effects of interventions on the quality of life of carers or simply that QALYs focus on an aspect of the carers’ lives (their health) that is unlikely to be affected by the interventions. It is argued here that narrowing the evaluative space to *health* for carers has the effect of conferring an ‘evaluation identity’ of *patient* on carers. This is inconsistent with supporting individuals in their caring role and neglects attributes of care-related quality of life (for example control, fulfilment and relationships).

QALYs offer a method of capturing the benefits to carers and patients in common units. For certain priority setting decisions where health maximisation is the goal this may be appropriate. However, when setting priorities across health and social care, where there are multiple objectives, focusing solely on health as a maximand may place carers at a disadvantage in resource allocation decisions.

1. Introduction

Family members and friends who act as unpaid (or informal) carers play an important role in maintaining the health and wellbeing of the population. In the UK, around six million people identify themselves as unpaid carers, with the incidence of caring peaking in the 45-60 age group.¹ Unpaid carers undertake a range of caring activities including: arranging formal care, doing extra housework and providing personal care (such as feeding, washing and toileting). The role of unpaid carers is becoming increasingly prominent in countries where governments are seeking community-based care solutions. In the UK, for example, a number of initiatives to support and acknowledge the role of carers were announced last year as part of a national carers' strategy.²

Carers have a somewhat ambiguous status in economic evaluation as they can be considered both an input into care and a group on whom outcomes of interventions may fall.³ Certain types of interventions, for example those that result in patient care being moved into the community, may increase the input of carers and under a societal perspective the additional opportunity costs of carers' time should, in theory, be taken into account.⁴ Interventions may also result in changes in the quality of life of carers, either directly, through interventions targeted at the carer themselves (such as respite care), or indirectly through the 'spillover' benefits of interventions that improve the health of the patient.

Quality adjusted life years (QALYs) are used in economic evaluation to capture the benefits of healthcare interventions in a single index combining life years and the (health-related) quality of life during those years. Because health is measured on a single scale QALYs allow interventions across a diverse range of clinical areas to be directly compared in terms of effectiveness and cost-effectiveness. NICE, in their guidance on the methods of technology appraisal now explicitly direct researchers to consider HRQL changes for carers: "*...when the impact of the treatment on the carer's health is also important.*" (NICE 2008, p.38).⁵ In other words, NICE recommends an evaluative space that potentially contains both patients and carers. The extension of the QALY approach to carers raises a number of positive and normative issues for economic evaluation. This paper draws on a review of empirical and theoretical literature on unpaid care and economic evaluation to address two issues. First, how have QALYs for carers been estimated and incorporated in economic evaluation to date? Second, is it *appropriate* to use QALYs as an estimate of benefits to carers?

2. QALYs and carers: empirical findings

Carers are rarely considered in economic evaluation, either on the cost side or on the outcome side.^{6;7} In rationalising this, it has been suggested that there are difficulties in estimating the amount of unpaid care,⁸ that unpaid care may be excluded due to the perspective⁷ and that the ongoing controversy over the valuation of time may discourage the inclusion of unpaid care.⁹ There are some examples of studies that have costed unpaid carers' time in economic evaluation,^{10;11} have used sum score measures to measure carer outcomes as part of an economic evaluation^{12;13} or have explored QALY effects on carers based on patient health status outside of an economic evaluation.¹⁴⁻¹⁶ This paper, however, focuses solely on the inclusion of carer QALYs in economic evaluation.

Eight studies were selected from the literature to illustrate some important issues in QALY measurement for carers. The eight economic evaluations cover interventions targeted at patients and interventions targeted at carers. The interventions cluster in three quite different areas of health and social care: two are economic evaluations of interventions for patients with Alzheimer's disease (AD),^{17;18} three are economic evaluations of rotavirus vaccination¹⁹⁻²¹ and three are economic evaluations of support and training programmes for carers.²²⁻²⁴ All but two of the economic evaluations have been published in the last five years.

Descriptive information about the eight studies is provided in table 1. The remainder of this section reviews the conduct and findings of the studies, covering three areas: the measurement of the carer's HRQL, the impact of the intervention on the carer's HRQL and the incorporation of carers' QALYs in the presentation of the findings.

Table 1: Economic evaluations that consider QALY gains to carers

<i>Study</i>	<i>HRQL measure and data collection</i>	<i>Presentation of findings</i>
Drummond <i>et al</i> 1990: Support programme for carers of elderly mentally ill	Caregiver Quality of Life Instrument administered during the trial	Only carer QALYs measured to generate ICER
Neumann <i>et al</i> 1999: Drugs to treat Alzheimer's disease	Health Utilities Index 2 (HUI2) scores from a cross sectional study of carers of patients with AD	Carer QALYs added to patient QALYs for sensitivity analysis.
Martikainen <i>et al</i> 2004: Family-based cognitive behavioural therapy for patients with Alzheimer's disease	Health Utilities Index 2 (HUI2) scores from a cross sectional study of carers of patients with AD	Authors concluded intervention was cost saving and therefore no ICER was calculated
Patel <i>et al</i> 2005: Training for carers of stroke patients	EQ-5D and EQVAS administered during the trial	Authors concluded intervention was cost saving and therefore no ICER was calculated
Newall <i>et al</i> 2007: Rotavirus vaccination in Australia	EQ-5D scores from a study of carers of parents of children with rotavirus disease in Canada	Authors concluded ICER (from healthcare perspective) was heavily dependent on inclusion of carer QoL
Jit <i>et al</i> 2007: Rotavirus vaccination in England & Wales	EQ-5D scores from a study of carers of parents of children with rotavirus disease in Canada	Authors aggregate child and parent utilities, but conclude vaccination is unlikely to be cost-effective for any realistic value of parameters
Charlesworth <i>et al</i> 2008 Befriending for carers of patients with dementia	EQ-5D administered during the trial	ICERs for intervention generated for carer QALYs and combined QALYs for carers and patients
Bilcke <i>et al</i> 2009: Rotavirus vaccination in Belgium	EQ-5D scores from a study of carers of parents of children with rotavirus disease in Canada	ICERs for intervention generated for carer QALYs and combined QALYs for carers and patients

Collection of HRQL data

To calculate QALY changes for carers, data were needed on the carer's HRQL. For all five of the studies where carers were not the prime target (the AD and vaccination studies) data came from separate studies of HRQL in carers. These data were then used in decision models to estimate the cost-effectiveness of the interventions. Data for the economic evaluations of the rotavirus vaccination programmes came from a Canadian study of the health of parents of children with rotavirus gastroenteritis.¹⁹ In the study, the EQ-5D was administered to the parents of the children three times over a two week period to investigate whether looking after a child with rotavirus gastroenteritis had any detrimental health impacts on the parents. For the AD trials, the data come from a cross sectional study of 528 carers of patients with AD.²⁵ The carers HUI2 scores were stratified by the disease severity of the patient (mild, moderate, severe) and location of care (community, institution) to investigate whether the carers' HRQL was affected by patient disease severity or location of care.

For the three studies of carer interventions (training, support and befriending) HRQL data were collected alongside the intervention study. In the training and befriending studies, the EQ-5D was administered to the sample of carers at baseline and at a number of follow-up points afterwards. For the carer support intervention, a carer-specific measure (the Caregiver Quality of Life Instrument) was developed prior to the study²⁶ and used to record each carer's quality of life at baseline and two follow-up periods afterwards. Responses were indexed onto a 0 to 1 scale through a time-trade-off exercise used alongside the profile measure.

Impact of intervention on carer QALYs

Across the majority of the studies the QALY effects on carers as a result of intervention were small: in seven out of eight studies, the difference between the intervention arm and the control arm was less than 0.02 on the underlying HRQL scale. The cross sectional study of AD carers' HRQL revealed that the carers' HUI2 scores showed very little variation by disease severity or the patient's location of care.²⁵ The mean HUI2 score was 0.86 for carers of patients in the community (regardless of whether Alzheimer's was mild, moderate or severe). This mean HUI2 score was only slightly higher for carers of patients in nursing homes (0.88 if AD was moderate/severe and 0.86 if AD was mild). The postulated impact of the two AD interventions on the carer's HRQL was via changes in the location of care and the

patient's disease progression. As the cross sectional study suggested neither care location, nor disease progression had an impact on the carer's HRQL, a negligible QALY effect on carers as a result of the interventions was incorporated in the models.¹

The economic evaluations of the training programme and the befriending studies used the EQ-5D data collected as part of the trials to measure the carer's HRQL. The authors of the training study found no differences in HRQL between carers in the intervention arm and the control arm when using the EQ-5D, although a significant difference favouring the intervention arm was found when using the EQVAS.²⁸ Furthermore, the clinical study revealed that the intervention also resulted in reduced levels of carer burden.²⁸ In the befriending study, a QALY difference of 0.017 was estimated (using the EQ-5D) between control and intervention group after 15 months. Notably, the mean QALY gain for the *care recipients* from the befriending intervention (also measured using the EQ-5D) was *larger* than for carers, at 0.051 QALYs over 15 months.

The cross-sectional study of parents of children with rotavirus gastroenteritis found a mean QALY decrement of 0.0018 (0.7 quality-adjusted days) resulting from the caring for someone with rotavirus gastroenteritis.²⁰ Though this appears tiny, it was only marginally smaller than the QALY losses for the children themselves, estimated at 0.0022 QALYs (0.8 quality-adjusted days) using a parent-completed HUI2. The small QALY impacts from rotavirus gastroenteritis result from the very low fatality rate and the small quality of life impact for a short time for non-fatal cases.¹⁹ EQVAS scores were also collected for carers and patients and these indicated somewhat larger QALY losses to both; these were incorporated in sensitivity analyses in two of the studies. As the QALY losses would not be entirely eradicated by vaccination, the estimated impact of vaccination on carer and patient QALYs was of a slightly smaller magnitude than would be suggested by aggregating the QALY decrements due to rotavirus gastroenteritis.

Of all the eight interventions considered, the largest QALY gains resulted from the support programme for carers. In this study, carers in the intervention group experienced an increase in quality of life from 0.55 to 0.64, while those in the control group declined from 0.56 to 0.53 over a period of 6 months.²⁴ The mean HRQL difference between the two groups by the

¹ This became the subject of much controversy as these HRQL weights were used to inform NICE's decision to limit the coverage of AD drugs in the UK²⁷

end of the trial was 20%. The authors judged this difference to be clinically important, however, the small sample size used (42) meant that even a difference of this magnitude was too small to be statistically significant. The authors noted a high variance in the responses to the CQLI meaning that larger sample sizes are required to establish significance at conventional levels;²⁴ in general, obtaining sufficient sample sizes for carer intervention research is a problem.²⁹

Aggregation and presentation of study findings

Different approaches were taken to aggregating and presenting the QALY gains to carers. The approach taken in two of the carer intervention studies was simply to treat the carers as the target group for the intervention and to restrict the evaluative space to just consider carer QALYs. In the economic evaluation of the training programme, the authors concluded that cost savings from the programme offset the costs of the programme. Although no gains on the EQ-5D were detected, other measures showed a tendency towards improved quality of life for the carers and therefore the authors did not calculate an ICER. In the economic evaluation of the carer support programme, the authors found that the intervention resulted in increased costs and additional QALYs for carers. An ICER was therefore calculated, which worked out at Can\$20,000/QALY. The authors noted that this ICER compared favourably to other healthcare interventions.

In the AD trials, QALY gains to carers were aggregated with patient QALYs to generate an overall estimate of health benefits from the interventions. In the AD drugs study this aggregation was conducted as part of their sensitivity analysis.¹⁷ As the QALY effects on carers were relatively trivial in comparison to patients, the inferences drawn about the provision of the interventions were not sensitive to the inclusion of the carer's QALYs. Similarly, in the rotavirus vaccination study in England, carer QALYs were added to patient QALYs. Including carer and patient QALYs in the evaluative space lowered the ICER (relative to including solely patients), but not sufficiently for it to make a difference around the critical range; the authors concluded that a strategy to vaccinate was not cost-effective under any realistic values of the model parameters.¹⁹

The Australian and Belgian studies of rotavirus vaccination also included both patient and carer QALYs in the evaluative space. Unlike the English study, this altered the ICER

estimates around the critical range. In the Belgian study, for example, the effect of including HRQL gains for two parents (carers) for each child increased the probability that Rotarix vaccination (one of two vaccinations) was cost-effective at a €50,000/QALY threshold from 2% to 89%. In the Australian study the cost-effectiveness of introducing Rotarix vaccination went from Aus\$122,000 to Aus\$40,000/QALY. In both studies the ICER was also highly sensitive to the decision to include one or two carers (parents) for each child. Despite the fact that the carer's QALY gains were small in absolute terms, the fact these were sizeable *relative* to the patient gains and also *relative* to the costs of vaccination, meant that the ICER (or probability of being cost-effective at the key threshold) was sensitive to the decision to include the carer's HRQL.

Finally, one study (the befriending study) took the reverse approach, and treated the carer's QALYs as the main measure of benefit but considered the patient's QALYs as part of the sensitivity analysis. When the carer's QALYs only were considered in the incremental analysis, an ICER of >£100,000/QALY was estimated for the intervention relative to standard practice. Adding the patient's QALY gains to carer's QALY gains, however, resulted in an ICER of £27,000/QALY. The study authors suggested that when evaluating interventions for carers, there may be good reason to expand the evaluative space to include patients, given the importance of the patient's wellbeing to the carers.²³

3. Normative issues

Most economic evaluations to date have not considered QALY gains to carers. The eight studies in this review that did consider QALY gains to carers used different approaches to measure QALYs and different approaches to aggregating and presenting the effects in the economic evaluation. The normative basis of these decisions and some implications of measuring carer QALYs are explored in this section.

Including carers in the evaluative space

If the goal of the economic evaluation is to inform decision-makers about how health can be maximised from limited resources, in theory there is little reason to exclude the carer's health (and by extension their QALYs) from the evaluation.⁷ It was suggested in one study that counting the carer's QALYs may lead to double counting when a societal perspective is employed as any productivity gains to the carer are counted twice.²⁰ This assumes

productivity gains are reflected in changes in HRQL status (and current evidence for patients suggests this is unlikely to be case).³⁰ Furthermore, it has been recommended that gains in leisure time for carers resulting from interventions should be estimated in the denominator of the cost-effectiveness ratio, for example through QALY changes.³¹

Under a payer perspective, as employed by NICE, indirect costs would normally be excluded. As stated earlier, NICE now explicitly directs researchers to consider health effects on carers (where significant). The 'where significant' is potentially important but currently unclear. There are significant opportunity costs to the collection of data and currently there is little evidence about the situations where spill-over health effects on carers are likely to be most significant. More research and guidance in this area could help to guide researchers in their decisions of whether to broaden the evaluative space in practice to consider carers.

A related issue is that once the decision has been made to consider carers, a decision has to be made about *which* carers to consider. Although a 'principal' carer for a patient will often exist, care may also be spread round many relatives and friends. Considering just a single principal carer for each patient may understate the level of unpaid care. In a recent study of care for dementia patients, more than half of all patients indicated that they received unpaid care from two or more people.³² As illustrated by the rotavirus vaccination studies, cost-effectiveness conclusions can be highly sensitive to the number of carers considered in the economic evaluation. The situation is further complicated by the fact some 'carers' do not identify themselves as carers and may simply see caring as a natural extension of their relationship with the patient.³³

Choice of HRQL measure

With the exception of the carer support study, QALYs were calculated using the EQ-5D or the HUI2. The EQ-5D covers five HRQL domains (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) and the HUI2 covers seven domains (sensation, mobility, emotion, cognition, self-care, pain, and fertility).

One issue that has been noted with the EQ-5D is the presence of a ceiling effect; none of the 243 health states lie between 0.88 and 1, suggesting that the EQ-5D is relatively weak at distinguishing good health states.³⁴ If the health state of the carer is relatively good, as one

may expect it to be if they are able to provide care, the EQ-5D may not therefore be very sensitive to any quality of life gains for carers. There also appeared to be scepticism about the *appropriateness* of the EQ-5D for estimating quality of life benefits to carers for economic evaluation. In the economic evaluation of the befriending programme for carers, Charlesworth *et al* for example report:

The main measure of quality of life for the trial was the EQ-5D. Given the limited information on the reliability and validity of the EQ-5D with the carer population, and the measure being limited to health related quality of life, broader measures of quality of life should be considered in any future research. (Charlesworth et al., p.41)²³

Scepticism has also been raised about the use of the HUI2 with carers, with the assertion made that the HUI2 is:

...somewhat limited by its orientation to physical health and its focus on long term health outcomes... the emotional component of the HUI2 [and the HUI3] (which we hypothesized should best capture caregiver burden), is only one of seven dimensions. (Bell et al.,p.134)³⁵

Other authors have also questioned whether HRQL measures are sufficient on their own to pick up the effects on carers of interventions. It has been argued that conventional HRQL measures are likely to neglect or diminish the importance of the psychological impacts and satisfactions of caring⁸ and fail to take account of preferences over the process of care.³⁶

There appear to be two inter-related concerns with using HRQL measures with carers. First, a concern that HRQL measures do not perform well in carers: i.e. they are not well-validated and may not be able to differentiate real underlying differences in carers' health. Second, a potentially more important concern, that HRQL measures diminish important and relevant aspects of the carer's quality of life by neglecting to measure them.

Carer-specific measures are sometimes used to record outcomes for carers in clinical trials. Among the most widely used are the Caregiver Strain Index,³⁷ Caregiver Reaction Assessment³⁸ and Sense of Competence Questionnaire.³⁹ Different measures tap into slightly different aspects of the caring experience, however, in general, measures tend to include

dimensions relating to: relationships, fulfilment, activities, support, finances, physical health and mental health.^{40;41} Whilst there are some overlaps in these dimensions with the dimensions that underpin HRQL measures there are also clear differences.

This raises the question of whether a measure of the caring experience or care-related quality of life (CRQL) should be used to underpin QALY estimates for carers. Drummond *et al*, in the study of the carer support programme, appeared to support this, suggesting that the ideal outcome measure for the economic evaluation of the carer support intervention would be “*a direct measure of the burden on carers*” (Drummond *et al*, 1991;212).²⁴ In that study, a CRQL measure, the Caregiver Quality of Life Instrument, was used to record quality of life for the trial. The descriptive system for the measure differs significantly from the HRQL measures, focusing on 5 attributes: of which health is just one (sleep, health, happiness, social (activities) and the relationship with the care recipient). As noted in section 2, the QALY impact of the carer support intervention on carers was of a much higher magnitude than in the other studies. As no HRQL measure was administered alongside the CRQL measure, it is impossible to say whether a HRQL measure would also have picked up this impact, however, it seems reasonable to assume that the impact was due in part to focusing on an evaluative space (care-related quality of life) that was more relevant to the goals of intervention.

The aggregation of carer and patient QALYs

The evaluative space in economic evaluation, in terms of “benefits to whom?”, is usually limited to patients.⁴² However, given the direction from NICE and the need to evaluate the cost-effectiveness of interventions to support carers, decisions have to be made about whether to aggregate carer and patient benefits. In some cases, where one intervention dominates, or when the effects on carers are negligible, adding carer QALYs to patient QALYsⁱⁱ will make no difference to the decision. In other cases, as in the evaluations of the befriending intervention and vaccination for example, the decision to aggregate carer and patient QALYs made a crucial difference to the ICER and therefore to the advice provided about the most efficient option. Generally, the decision about whether to aggregate carer and patient effects will be critical either when the point estimate for the ICER is close to the threshold, or when carer and patient QALY changes are of a comparable magnitude. Furthermore, the befriending study and the vaccination studies both demonstrate that the ‘spillover’ HRQL

ⁱⁱ This point and the remainder of the discussion in this section equally applies when considering the carer as the prime target and spillover effects on patients

changes of interventions can outweigh the HRQL gains for the 'primary target' of the intervention.

There are at least three implications of moving from a position where the evaluative space is limited to patient QALYs, to one where it contains patient and carer QALYs. First, aggregation will inflate the magnitude of the benefits from healthcare interventionsⁱⁱⁱ reducing ICERs and pushing a number of interventions that were not previously cost-effective under a given cost-effectiveness threshold (as seen in the studies by Charlesworth *et al* and Bilcke *et al*)^{21;23}. In this case, there may be a need to revise the threshold for adopting new interventions.²⁰ Second, if carer and patient QALYs are aggregated selectively in some studies and not others, ICERs will be lower where aggregation took place and therefore resources may be diverted to interventions simply because analysts took the decision to broaden the evaluative space. A third, normative, implication of aggregating carer and patient QALYs is that it could lead to a relative shift in provision to interventions and patient groups where there were larger (positive) spill-over effects. From an efficiency point of view this may be desirable; however, the equity implications may be unpalatable to decision-makers. For example, it could mean patients without family carers would receive a lower priority in resource allocation. To address the aggregation issue, it seems appropriate to present carer and patient QALYs in both disaggregated and aggregated formats, with as much clarity as possible provided to decision-makers to interpret the ICERs.

4. Carers and their 'evaluation identity'

Several authors expressed a concern about the appropriateness of using HRQL measures to capture the effects of interventions on carers for economic evaluation. The concern seems to centre on the fact that health, as an evaluative space, does not cover important aspects of carers' quality of life which are of concern for resource allocation decisions. This concern is elaborated on in this section, by focusing on what we have termed carers' 'evaluation identity'. We suggest that a health evaluative space has the potential to disadvantage carers in resource allocation decisions and that the use of measures that reflect functionings more relevant to carers should be encouraged.

ⁱⁱⁱ If the spillover effects on carers are negative, the implications are reversed

Cost per QALY analysis operates in an extra-welfarist paradigm, a departure from classical welfare economics, allowing benefits other than utility alone to be considered in the evaluative space.⁴³ When working within the extra-welfarist paradigm, researchers start by making a decision about what to include in the evaluative space.⁴⁴ Sen advocates considering individuals' capabilities (to carry-out key functionings) in the evaluative space.⁴⁵ Culyer has linked QALY-based analysis to Sen's work, suggesting that for healthcare resource allocation decisions, health is a key functioning to work with in the evaluative space (albeit not necessarily the only one).⁴⁶ Qualitative exploration of the caring experience has suggested that key attributes of the caring experience (for carers) centre on process-based issues, relating to their relationship, fulfilment, control, ability to engage in outside activity and support that they receive.⁴⁷ These closely correlate with the dimensions of existing carer-specific measures. Whilst health may be an argument of in care-related quality of life it does not appear to be of primary importance.

One way of thinking about the issue is that the focus on health was developed as a pragmatic way of evaluating the benefits of healthcare to 'patients'. Extending the same evaluative space to carers has the effect of placing a 'patient' identity on carers in the economic evaluation. This misrepresents their role as a carer and consequently what functionings are important to them and how interventions affect their wellbeing. Instead, assigning carers an evaluation identity of 'carer' implies measuring benefits to them in terms of a set of functionings, which could be summed up as 'care-related quality of life' or the 'caring experience'. The argument is fundamentally different to that for condition-specific measures; arguably health is the wrong evaluative space *per se* for carers and is not 'merely' too broad or generic.

A potential difficulty with using a care-related quality of life evaluative space for carers is that it conflicts with a goal of pure health maximisation. It has been argued that the focus on health in economic evaluation is justified by public policy objectives in healthcare,^{48;49} While this superficially has appeal, it fails to mirror the fact that healthcare is intrinsically linked with social care (both in terms of the delivery and funding)⁵⁰ and that there are multiple objectives for health and social care policy.^{51;52} While it is true that some government policies (in the UK) focus on health gain, such as targets to reduce cancer and coronary heart disease mortality, others emphasise reductions in waiting times and community-based care for older people.⁵¹ As analysts are increasingly being asked to evaluate the cost-effectiveness of

interventions across the health and social care spectrum⁵² the argument that health and social care services are solely there to maximise health becomes less tenable.

A second argument deployed to support the practice of health maximisation in economic evaluation is that individuals display paternalistic altruism with respect to others' health.⁵³ The argument is made that individuals would prefer to see the health or access to healthcare improved for others, more than other individuals' welfare measured in some broader way. However, displaying paternalistic altruism with respect to others' health does not preclude the fact that individuals may also want to see the other aspects of other people's lives improved (for example their caring experiences). When lay people, professionals and hospital managers were asked to prioritise interventions that included those targeted at carers and patients, all these groups placed a higher priority on providing respite for carers of older people compared to some other interventions that would more obviously result in health gain, such as hip replacements and treatment for schizophrenia.⁵⁴

When setting priorities between interventions targeted at patients and interventions targeted at carers, the use of a health evaluative space has the potential to lead to inequity in resource allocation. For carers, the use of a health evaluative space has the effect of creating a double-hurdle in resource allocation decisions, in that not only must a policy that benefits them be sufficiently beneficial for it to justify the additional costs, the benefits must also be expressed through health gain. Thus interventions for the carer that left the carer feeling more in control and/or more fulfilled from caring could have significant benefits for the carer, yet these benefits would be neglected by the use of health as the evaluative space. Practical examples of such policies may include greater engagement of the carer in treatment or care decisions for the patient⁵⁵ or training programmes for the carer.²

5. Discussion and recommendations

Currently, the use of QALYs with carers appears to be limited and ad hoc; studies across a disparate array of areas have taken into account QALY effects on carers, using different measures and making different decisions about the way that QALYs are aggregated and presented. In general, the QALY gains to carers are small, but this is not to say insignificant, either relative to patients or for the purpose of decision-making. The small effects are also

likely to arise in part from the evaluative space of health. We have argued that health is a potentially inappropriate evaluative space for carers and (because interventions for carers are not necessarily designed to improve their health) has the potential to place carers at a disadvantage in resource allocation.

Analysts will be faced with a situation where they are evaluating a patient-focused intervention and need to decide whether to consider the spillover effect on carers. If there is clear direction that the goal of the economic evaluation is to inform the maximisation of health benefits, it will in theory be appropriate to measure (health) QALYs for carers. As suggested previously, it may be appropriate to present two ICERs in the analysis, one which includes patient QALYs and one which includes patient and carer QALYs. Currently there is little clarity about the situations in which effects on carers are likely to be important, whether analysts should go beyond a principal carer for each patient, whether carer and patient QALYs should be aggregated and if so, whether the threshold for adoption of healthcare interventions should be revised. Further research and direction on these issues would be helpful. If the decision is made to conduct a standard cost-utility analysis and the spillover effects on carers are thought to be important, it may be useful to collect CRQL on the carer. This can be presented alongside the cost-utility analysis in a cost-consequence format,⁵⁶ providing information to decision makers who wish to consider any additional quality of life effects on carers.

Following earlier work to measure CRQL for economic evaluation,²⁶ further measures of the caring experience are starting to be developed for use in economic evaluation.^{41;47} Although such measures are in their infancy, they have the potential to focus on an evaluative space that is more relevant to carers. These measures may be useful either for recording CRQL as part of a cost-consequences analysis (as described above) or as the primary outcome for economic evaluations designed to inform priority setting for carer support. As such measures focus on CRQL they could help inform decisions about how budgets could be spent to maximise the benefits to carers.

Both the HRQL and the CRQL approaches to measuring benefits to carers have weaknesses: the HRQL approach implicitly assumes carers have a 'patient evaluation identity', while the

CRQL approach results in carer and patient benefits being denominated in different units^{iv}. This is problematic if making priority setting decisions across health and social care. An alternative is therefore to use a broader common denominator, such as general quality of life^v. Broader quality of life or wellbeing measures often include dimensions related to autonomy/control and relationships^{57;58} and therefore potentially encompass an evaluative space that is more relevant to carers (as well as patients). However, few general quality of life measures are preference-based and therefore arbitrary assumptions are made about the relative importance of the different dimensions. Recent work based on the capability approach has looked at specifying a broader evaluative space for economic evaluations in public health⁵⁹ and developing an index measure of quality of life for older people.⁶⁰ Such approaches may offer a promising way forward for setting priorities across health and social care, where benefits to patients and carers need to be considered. These measures are, however, largely untested and may also be inappropriate if specific goals (such as improvements in health or care-related quality of life) are set for the spending.

In conclusion, we suggest that caution should be exercised in estimating QALY gains to carers, with the assumptions behind ICERs clearly detailed (what HRQL measure was used? Were carer and patient QALYs aggregated? How many carers were considered?) We also suggest that care-related quality of life measures and general quality of life measures may be more appropriate primary outcomes for carers when informing resource allocation decisions where health maximisation is not the explicit goal.

Suggested discussion points:

- Are any people currently collecting quality of life data for carers and what plans do they have for presenting this in the analysis?
- What determines researchers' decisions to collect carer QoL data in the first place?
- Should the focus of the paper be on empirical studies, normative, or both?

^{iv} Unless CRQL states are also scaled to death and 'full health' and are assumed to be commensurate with HRQL states

^v If operating in a welfarist paradigm, utility could also be used (as measured through willingness-to-pay or experienced utility)

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