Carer utilities in cost-utility analyses (CUAs): Crucial information or additional burden of uncertainty?

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None of the authors report conflict of interest.

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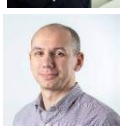

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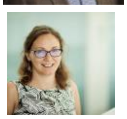

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CARER UTILITIES: EXPERIENCE AND UNCERTAINTIES

PREFERENCE-BASED OUTCOME MEASURES FOR FAMILY CARERS

CAREGIVER BURDEN: MEASUREMENT CHALLENGES & ISSUES

ETHICAL AND METHODOLOGICAL QUESTIONS AROUND IMPLEMENTATION OF CARER UTILITIES

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Audience questions

1. Have you ever contemplated the inclusion of the impact of a technology on carer(s) in an evaluation? – Please choose one:
   a. No, never
   b. Yes, qualitatively (e.g. described it in the text of the submission)
   c. Yes, quantitatively, but not as part of the economic evaluation (e.g. the impact was measured)
   d. Yes, quantitatively as part of the economic evaluation (i.e. included in the ICER)
2. If you have considered inclusion of impact on carers, were you ever deterred from actual inclusion?
   a. Yes
   b. No
3. What do you see as the major barriers to the inclusion of impact on carers in technology assessments? – Choose all that apply:
   a. Unclear definition of carer
   b. Unclear definition of impact on carer
   c. Uncertainties in measurement
   d. Uncertainties in implementation in economic evaluation
   e. Issues with comparability across other areas where carer impact was not taken into account
   f. Uncertainty about acceptability of carer impact by HTA agencies
   g. Other

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CARER UTILITIES: EXPERIENCE AND UNCERTAINTIES

17 November 2020

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Carer utilities: Spillover effect

- Economic evaluations usually take into consideration the costs for health-care payers health consequences for patients
- Informal care however can be an important aspect of various health conditions and can have consequences on
  - Costs: informal care costs
  - Health consequences on others, including
    - Caregivers
    - Non-care-giving family members

  Spillover effects[1]
- Health consequences can include[2]:
  - Effect of caregiving
  - Effect of caring about others
  - Combination of the two
- Exclusion of these can provide misleading information on the effect of a healthcare intervention

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Sources: 1 Basu and Meltzer 2005, Wittenberg 2019

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Carer utilities in HTA: Explicit guidance

	Explicit guidance on inclusion?	Specific methods guidance?	Details
Norway - NoMA	✓	✓	Can be accounted for and can be quantified in QALYs Results must be presented with and without "how changes in the patient's health-related quality of life affects the health-related quality of life of the caregiver(s)" Effect of life expectancy of the patient, should not be taken into account.
UK – NICE	✓	✗	"All direct health effects, whether for patients or, when relevant, carers"
UK – SMC	✓	✗	"need to be presented separately from the primary QALY analysis as it is outside the perspective"
USA – ICER	✓	✗	"Specific scenario analyses (e.g., using a modified societal perspective that incorporates estimates such as productivity losses, caregiver burden, and other indirect costs) and subgroup analyses are conducted when appropriate."
Australia – PBAC	✓	✗	"in circumstances where the beneficiaries of health or other relevant outcomes are broader than the treated patient population (eg community, carers, dependants), include these as supplementary analyses" (Appendix 6)
Canada – CADTH	✓	✗	Spillover effects to carers can be included and effect included in a non-reference case analysis Carers can be part of the target population in decision problem
Belgium – KCE	✓	✗	"effects on caregivers' health-related quality of life can be presented as complementary analyses but are not acceptable in the reference case" "It should then be explicitly stated that the QALY estimates include the effect on caregivers' health-related quality of life."

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Carer utilities in HTA: Implicit mention through perspective/Not mentioned

	Explicit guidance on inclusion?	Specific methods guidance?	Details
Netherlands – TLV	✗	✗	"All relevant societal costs and benefits, irrespective of who bears the costs or to who the benefits go, should therefore be taken into account in the evaluation and reporting."
France – HAS	✗	✗	"The reference case analysis adopts a collective perspective that is sufficiently broad to take into account all stakeholders concerned by the treatments studied […] The health effects are identified and measured from the perspective of individuals affected by the interventions. "
Ireland – NCPE	✗	✗	"all health effects accruing to individuals[…] should be included in the outcomes for the reference case"
Germany - IQWiG	✗	✗	-

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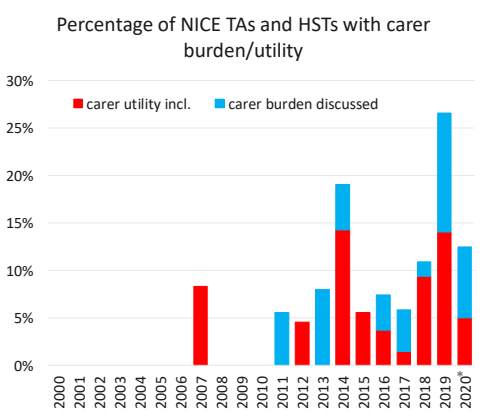
Carer utilities in NICE assessments

- Review of NICE technology appraisals (TAs) and highly specialised technology (HST) appraisals
  - 2000-2018: Pennington et al. 2020
  - 2019-2020: Additional review*
- Documents
  - Final Assessment Determination (FAD) for TAs
  - Final Evaluation Determination (FED) for HSTs
- Suggests increasing interest in carer burden, but not so much in carer utilities
- Disease areas, with carer utilities
  - 2000-2018:
    - Mostly rare, genetic and congenital conditions, multiple sclerosis, etc.
  - 2019-2020:
    - Mostly rare, genetic and congenital conditions, multiple sclerosis
- Burden mentioned in various other indications
- Caution in incorporation into QALYs



Source: 2000-2018: Pennington et al. 2020
*2020 not complete: until 21 October

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Evidence vs. HTA use

Carer utilities available in literature (-2018)

- Rare genetic and congenital conditions (24%)
- Alzheimer disease and dementia (19%)
- Cancer (8%)
- Stroke (5%)
- Arthritis (4%)
- Gastrointestinal conditions (4%)
- Multiple sclerosis (4%)
- Etc.

Carer utilities used by NICE (-2020)

- Rare genetic and congenital conditions (44%)
- Multiple sclerosis (41%)
- Alzheimer disease and dementia (4%)
- Arthritis (4%)
- Atopic dermatitis (4%)
- Disease-related splenomegaly or symptoms in adults with myelofibrosis (4%)

Burden discussion, not quantified

- Cancer (41%)
- Asthma (14%)

Sources: Wittenberg 2019, Pennington 2020

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Questions and uncertainties: Measuring

- What is the spillover effect of the new health technology
  - Separating the impact from the carers underlying health conditions (e.g. elderly carer)
  - Separating the effect of patients' health from carer burden: Double counting?
  - Effect of change in patients' quality of life (e.g. severely ill children)
  - Effect of patient's prognosis: caring for a child with disability vs. end of life care for an elderly relative
- Who is affected:
  - Number of carers
  - Distribution of burden between family members
  - Distribution of burden between paid carers or different family members
- Elicitation
  - Direct: mapping preferences directly onto the utility scale (e.g. standard gamble, time trade-off)
  - Indirect: mapping preferences to the utility scale indirectly via a generic health related quality of life questionnaire (e.g. EQ-5D)

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Questions and uncertainties: Implementation

- What are the carer health states/events? What if they are different than for patients?
- Disutilities vs. utilities
  - For disutilities: what is the baseline?
- Additive vs. multiplicative effect
- Ethical considerations
  - Effect of life extension of patients on carers
  - Different effects on carers vs. patients
    - E.g. after-effects of meningitis incurred by patients and their carers: amputations vs. behaviour problems[1]
    - E.g. End of life care
- Equity considerations:
  - Treatments in diseases that affect carers have a bigger impact
  - Focus on carers only vs. societal perspective

Source: 1 Al-Janabi 2016

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Conclusions

- Comparison with prior technology appraisals with no carer burden can be problematic
- No gold standard in:
  - Definition
  - Elicitation
  - Implementation
- Limited current discussions, though there is some research ongoing
- HTA attitude is complex
  - Many HTAs: good idea in theory
  - However challenges and uncertainties reduce the probability of their acceptance
  - importance of being comfortable with its use in a disease area

More research and further discussions are needed

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Audience question

4. Which area should be the priority for future research and/or guidance? - Please choose one:
   a. Definition of carer
   b. Definition of impact on carer
   c. Guidance on measurement
   d. Guidance on implementation in economic evaluation
   e. Guidance on how inclusion of carer impact influences cost-effectiveness threshold or comparison with other disease areas
   f. Other

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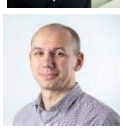

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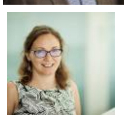

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