Background

While health technologies are targeted at improving patient health-related quality of life (HRQoL), it is increasingly acknowledged that treatments can also benefit individuals within the patient’s network, such as caring and non-caring family members. The 2022 National Institute for Health and Care Excellence (NICE) methods guide\(^1\) states that health effects in others, particularly carers, should be considered when relevant. A review of NICE appraisals by Pennington (2020)\(^2\) showed that in practice the inclusion of carer HRQoL in cost-utility analysis (CUA) is rare. We aimed to establish the use of carer HRQoL in NICE appraisals since 2019.

The NICE 2022 methods guide\(^1\)

“Evaluations should consider all health effects, whether for patients or, when relevant, other people (mainly carers)”

“When presenting health effects for carers, evidence should be provided to show that the condition is associated with a substantial effect on carer’s health-related quality of life and how the technology affects carers.”

Methods

Technology appraisals (TAs) and highly specialized technologies (HSTs) published between January 2019 and March 2022 were screened for the inclusion of carer HRQoL, following the approach described in the article by Pennington\(^2\). Justification, methods and data sources for the inclusion of carer HRQoL were extracted and analysed.

Results

In the Pennington review\(^2\), 3% (12/414) of TAs and 50% (4/8) of HSTs included carer HRQoL in the CUA, this increased to 6% (13/226) of TAs and 78% (7/9) of HSTs in our update. The conduct of de-novo HRQoL studies as opposed to the use of HRQoL estimates from published sources became more prevalent (7/20). Moreover, inclusion of carer HRQoL is more frequently seen in the base-case (19/20) than in scenario analysis only. HRQoL was most frequently measured using EQ-5D weights (16/20) and less often with EQ-VAS, time trade-off (TTO) or HUI derived values. Carer HRQoL was often modelled as a function of a patient’s disease severity, other methods included linking carer HRQoL to treatment arm or treatment response, clinical event, patient’s death or a combination of methods. Whether NICE accepts the inclusion of carer HRQoL often hinges on the perceived credibility of the input parameters and assumptions.

Conclusions

The inclusion of carer HRQoL is becoming increasingly prevalent in NICE appraisals, but is still uncommon in TAs. The robustness of the evidence on carer HRQoL values and the prevalence of informal care use is pivotal for inclusion in the base-case analysis.

References
