

# Understanding the Disconnect: Characterizing Trends in Inclusion of Family and Informal Caregiver Spillover in US Value Assessments

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Cheng, Spencer<sup>1,2</sup>; Pandey, Rajshree<sup>3</sup>; Kang, Ashley<sup>3</sup>; Kowal, Stacey<sup>2</sup>

<sup>1</sup>The CHOICE Institute, Department of Pharmacy, University of Washington, Seattle, WA; <sup>2</sup>Genentech, South San Francisco, CA; <sup>3</sup>Curta Inc., Seattle, WA

## BACKGROUND

- Informal caregiver burden and family spillover is increasingly recommended as an instrumental value element for cost-effectiveness analyses and health technology assessments from the societal perspective<sup>1,2</sup>
- In 2020, the Institute for Clinical and Economic Review (ICER) updated their value assessment framework to explicitly include elements of caregiver burden and family spillover<sup>3</sup>
- Although increasing amounts of information on caregiver burden are collected and shared by patient and caregiver advocacy groups, it is unclear how this information is incorporated into United States (US) value assessment reports

## OBJECTIVE

This review sought to characterize the inclusion of family and informal caregiver spillover effects in value assessments conducted by ICER

## METHODS

We conducted a targeted thematic analysis of ICER value assessments published between February 2019 and April 2023 that evaluated a pharmaceutical drug (no medical devices or diagnostics)

### Step 1: Review ICER report sections

- Long-term cost effectiveness (model inputs)
- Other relevant information (patient and caregiver perspectives, potential other benefits, contextual considerations)
- Public comments (submitted by patient advocacy groups)

### Step 2: Characterize spillover type

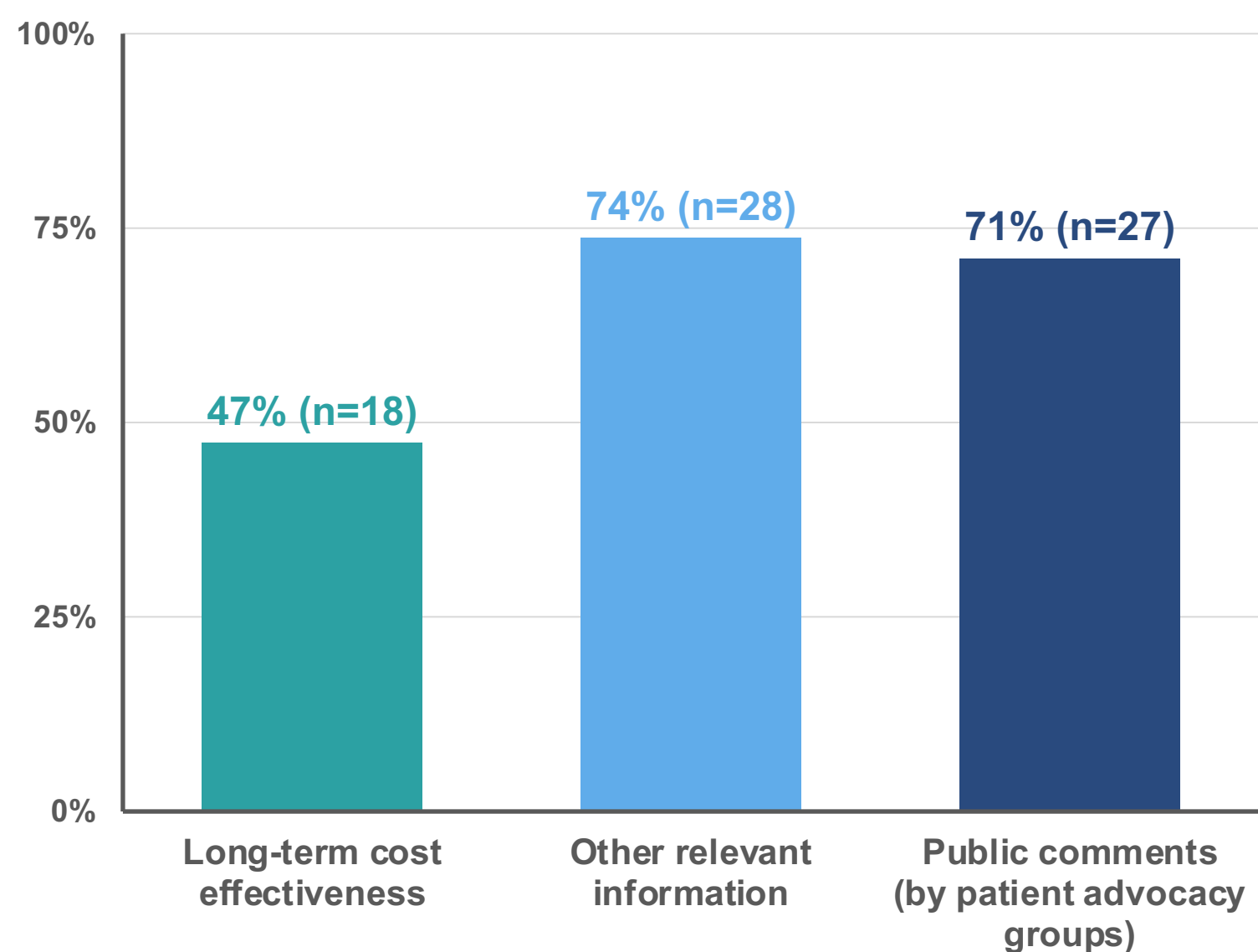
- Financial burden (unpaid caregiver time or direct costs)
- Quality of life
- Productivity
- Health
- Opportunity cost
- Nonspecific impact\*

\*Not containing any information on the type of spillover information that fits into the prespecified categories (eg, "burden," "impact")

## RESULTS

- A total of 38 reports were reviewed, and 31 (82%) included information on family spillover effects
- Although these effects were highlighted in most public comments by advocacy groups (71%) and discussed qualitatively in the relevant sections of ICER reports (74%), caregiver burden was only integrated in the economic models in 47% of assessments (Figure 1)

Figure 1: Family Spillover Inclusion by ICER Report Section (N=38)



### Family Spillover Characterization (Figure 2)

- The long-term cost-effectiveness analyses solely reported unpaid caregiver time and costs (n=11; 61%), productivity (n=11; 61%), and quality of life (n=8; 44%)
- The other relevant information sections included broader burden elements including health and opportunity costs
- The public comments underscored financial burden (n=15; 56%), quality of life (n=13; 48%), and productivity (n=12; 44%), but several reports had information that was not characterized (n=20; 74%)

Figure 2: Family Spillover Elements by Section

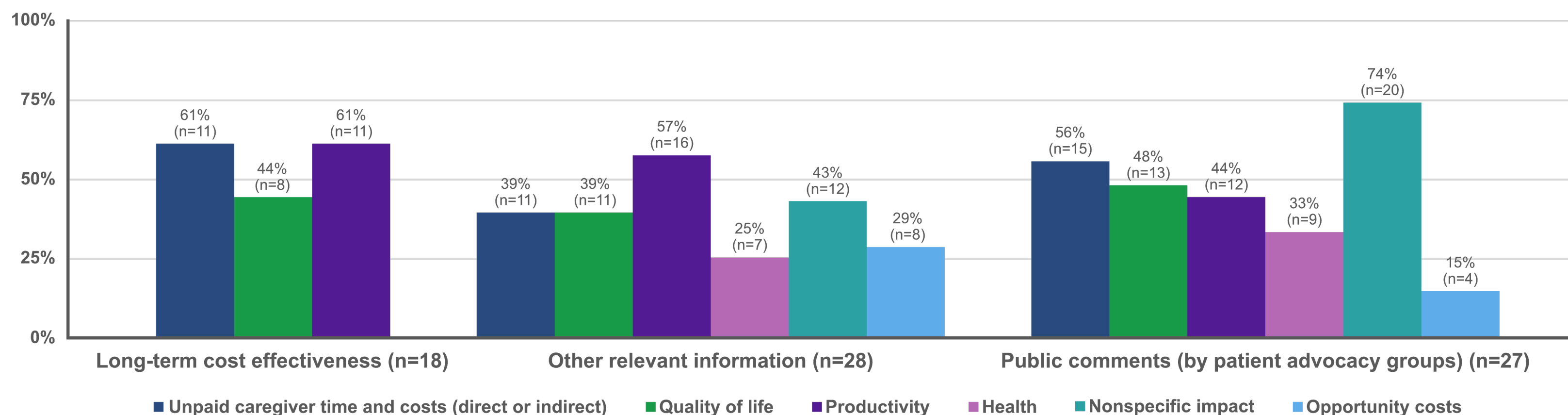


Table 1: Examples of Caregiver Spillover Characterization

	Long-term cost effectiveness	Potential other benefits and contextual considerations	Public comments (by patient advocacy groups)
<u>Duchenne Muscular Dystrophy (2019)</u> <sup>4</sup>	<b>[Quality of Life]</b> Caregiver utilities elicited from the EuroQoL-5 Dimension 3 level (EQ-5D-3L) in a prior study and correlated with patient health states: early ambulatory, late ambulatory, early nonambulatory, and late nonambulatory; the utility values were 0.845, 0.839, 0.784, and 0.810, respectively  <b>[Unpaid Caregiver Time and Costs]</b> Costs to caregivers in base-case modified societal perspective were used from the same study and included costs for nonmedical community services, informal care, indirect costs of illness, and out-of-pocket costs for home alterations by health states used for quality of life	<b>[Health]</b> "The high caregiving burden for patients with DMD was often mentioned, including the anxiety, depression, and isolation that can result from caring for a child (or children) with a severe illness"  <b>[Productivity]</b> "Reduced caregiver burden may lead to greater ability of caregivers to continue working/return to work"	<b>[Productivity]</b> "In addition to direct costs, Duchenne was also associated with large productivity losses, for both patients and caregivers"  <b>[Health]</b> "It has a cascading effect on the patient with Duchenne, affecting everything from ambulation, to the ability of caregivers to lift and transfer the patient, to the social and psychological well-being of both the patient and his family"
<u>Sickle Cell Disease (2020)</u> <sup>5</sup>	<b>[Quality of Life]</b> Assumption that caregivers experience a 10% disutility of that experienced by patients  <b>[Productivity]</b> It was assumed that for each acute pain event the caregiver would miss 7 days of work	<b>[Opportunity Costs]</b> "Family members described the tremendous responsibility of caregiving, including the need to leave the work force to provide care for their loved one while facing the impact of lost wages and significant out-of-pocket expenses" <b>[Unpaid Caregiver Time Costs]</b>	<b>[Health]</b> "Likewise, there are notable financial and emotional burdens on the caregivers and families of patients with SCD"
<u>Migraine: Acute Therapies (2020)</u> <sup>6</sup>	<b>No caregiver data included in long-term cost effectiveness</b>	<b>[Nonspecific Impact]</b> "New therapies for acute treatment of migraine may reduce caregiver and family burden if outcomes are improved for those in whom existing therapies do not effectively and safely control symptoms"	<b>[Nonspecific Impact]</b> "The unmet need in this vulnerable population results in pain, disability, and high individual, family, societal, and economic burden"

## CONCLUSIONS

- Recent ICER assessments routinely include information on informal caregiving spillover effects, and themes largely align with information submitted by patient advocacy organizations
- However, these effects were less frequently included in economic models, which may lead to challenges in understanding how caregiver burden impacts burden of disease across assessments
- Our findings suggest the need for alignment between ICER, advocacy organizations, and researchers on the specifications of the data needed to ensure that key family spillover themes can more routinely be included in economic evaluations and standardized in US value assessments

## LIMITATIONS

- This review did not explore inclusion of elements over time or as a function of the disease type (eg, oncology vs rare disease vs chronic condition)
- We measured the frequency in which family spillover effects were included across assessments but did not quantify the magnitude of the effect within each report or how it should be valued

## DISCLOSURES

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## ACKNOWLEDGMENTS

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