BEYOND PATIENT OUTCOMES, THE GROWING RECOGNITION OF CAREGIVER IMPACT IN OUTCOMES RESEARCH

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CAREGIVER IMPACT ASSESSMENT IN NUMBERS

126
Caregiver-focused COAs

~2 ×
COAs developed in 2010–2019 vs. 2000–2009

84%
disease-specific in 2015–2025

25%
address CNS disorders

71%
target caregivers of adults

WHY DOES IT MATTER?

Capturing caregiver impact helps reveal important consequences of disease and treatment that patient outcomes alone may not reflect.

WHAT WAS OUR OBJECTIVE?

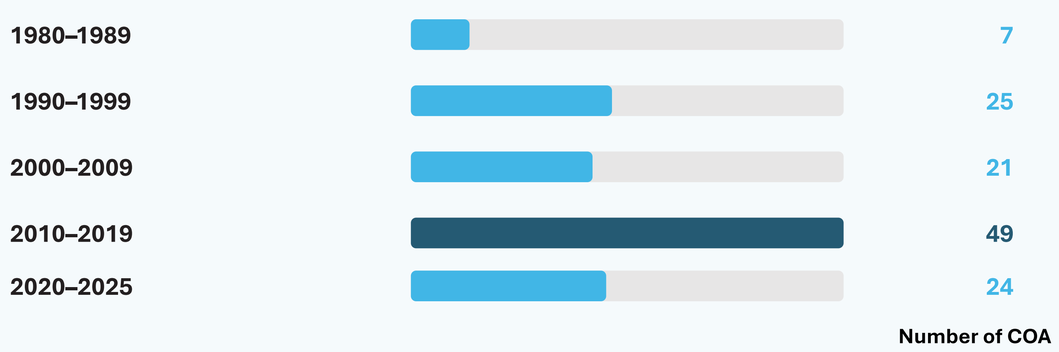
- Characterize trends in caregiver burden- and impact-focused COAs.
- Examine COA development over time, therapeutic area, and age category.
- Explore the shift toward non-disease and disease-specific assessment.

HOW WAS IT DONE?

- **Sources**: COA database PROQOLID™ and PubMed systematic reviews.
- **Inclusion criteria**: COAs assessing caregiver burden or impact
- Analyzed by year, disease specificity, therapeutic area, and age group.

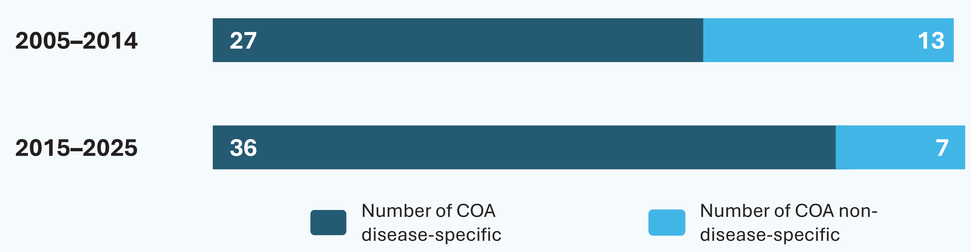
RESULTS

Caregiver-focused COAs development accelerated over time



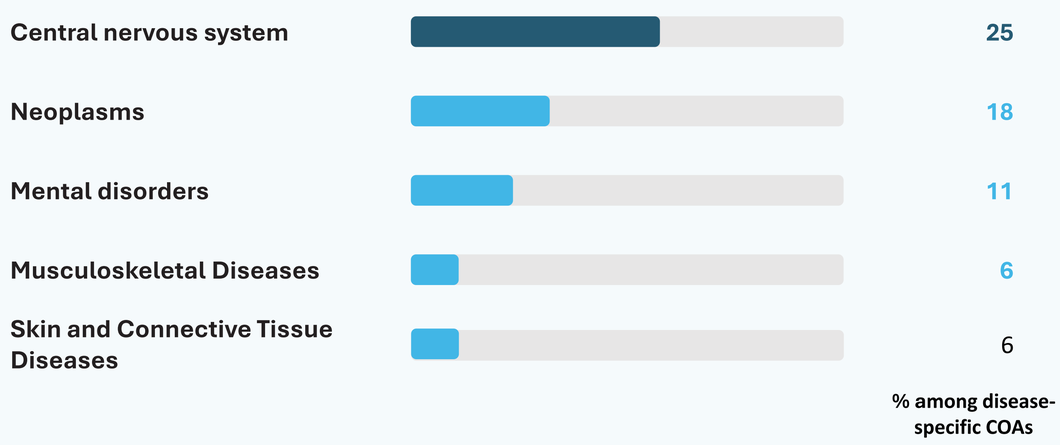
KEY MESSAGE | Post-2009 marked a notable shift, with 73 COAs developed.

Assessment is increasingly disease-specific



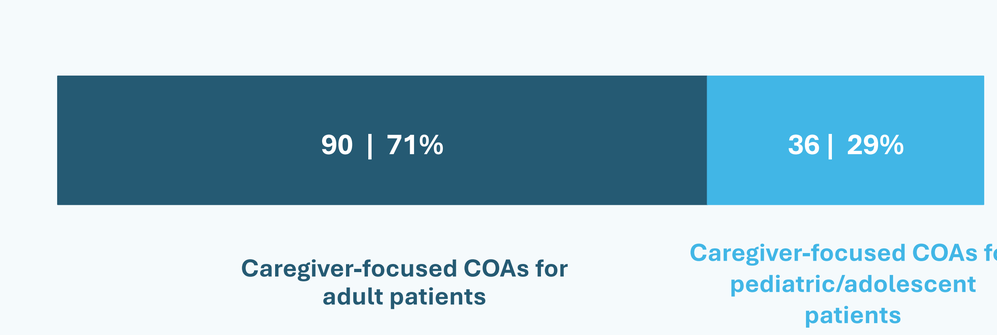
KEY MESSAGE | 84% COAs were disease-specific in 2015–2025.

Neurological conditions lead caregiver-focused COAs development



KEY MESSAGE | CNS, cancer, and mental health account for 54%.

Pediatric caregiving remains underrepresented



KEY MESSAGE | Only 29% COAs target pediatric caregiving.

EXAMPLES OF CAREGIVER-FOCUSED COAS

- **Non-disease specific measures :**
  - Caregiver Work Limitations Questionnaire (Caregiver WLQ) - *To assess the impact of caregiving on work performance and productivity (2014)*
  - Caregiver Quality Of Life Questionnaire (Physical & Emotional) (CQLQ) - *To assess physical and emotional quality of life in caregivers (2016)*
- **Disease-specific measures**
  - CareGiver Oncology Quality of Life questionnaire (CarGOQoL) - *To measure the quality of life of the caregivers of patients with cancer (2012)*
  - Growth Hormone Deficiency-Parent Treatment Burden Measure (GHD-PTB) - *To assess treatment burden of parents living with children with Growth Hormone Deficiency (2023)*
- **Measures used in a neurological condition**:
  - Zarit Burden Interview (ZBI-22): *To assess the level of subjective feelings of burden experienced by caregivers of older persons with dementia and other types of disability (2018)*
  - Schizophrenia Caregiver Questionnaire (SCQ): To assess the impact of caregivers on caring for patients with schizophrenia (2013)
- **Measures used in pediatric population:**
  - Assessment of Caregiver Experience with Neuromuscular Disease (ACEND) - *To assess experience of caregivers of children with neuromuscular disease (2011)*
  - Caregiver Burden Scale for Parents of Children Who Stutter (CBS-PCWS) - *To measure caregiver burden associated with parenting a child who stutters (2022)*

WHAT DOES THIS MEAN?

- Caregiver experience is gaining recognition as an outcome in health research.
- Disease-specific COAs support increasingly tailored assessment.
- Further development is needed in underrepresented therapeutic areas and pediatric populations.

TAKEAWAY

Caregiver impact is not a side story.

It is part of the treatment evidence.

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