

Landscape analysis of Alzheimer’s disease-specific caregiver outcome assessments

EPH131



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Background

Approximately 80% of people with Alzheimer’s disease (AD) and related dementia rely on caregivers.¹ In Europe, caregivers provide 0.9 – 5.0 hours per day of informal care for patients with dementia.² Longitudinal studies have shown that their health-related quality of life (HRQoL) negatively trends over time.³

Using caregiver outcome assessments (CareOAs) in AD trials can capture the impact of treatment on caregiver burden, HRQoL, and time spent providing care. This abstract aims to conduct a landscape analysis of AD-specific CareOAs to evaluate the content of available assessments and inform future selections for clinical trials.

Methods

Assessments were identified through PROQOLID database on eProvide and Google Scholar. Search terms “caregiver”, “caregiver burden”, and “caregiver quality of life” were used, and results were filtered by therapeutic indication (AD). Two researchers extracted properties of the assessments from PROQOLID.

Results

- Ten AD/dementia CareOAs were identified, including Caregiver-Perceived Burden Questionnaire⁴ (CPBQ), Dependence Scale⁵ (DEPS), Alzheimer’s Disease Caregiver Preference Questionnaire⁶ (ADCPQ), Marwit Meuser Caregiver Grief Inventory⁷ (MM-CGI), Impact of Alzheimer’s Disease on Caregiver Questionnaire⁸ (ADCIQ), Zarit Caregiver Interview for Alzheimer’s Disease 27⁹ (ZCI-AD-27), Resource Utilization in Dementia¹⁰ (RUD), Resource Utilization in Dementia (RUD) Lite^{10, 11}, Revised Memory and Behavior Problem Checklist¹² (RMBPC), and Partner-Patient Questionnaire for Shared Activities¹³ (PPQSA).
- Most had reported development evidence (Figure 1), including caregiver (e.g., focus groups and interviews) (n=4), clinician input (n=5), literature (n=7) and/or prior instrument review (n=7).
- The CareOAs contained between 12 to 71 items and recall periods ranged from the present to four months: one referenced, “over the course of the study”. Response options for the CareOAs included Likert scales (n=6) or dichotomous response scales (n=3).
- CareOAs measured various outcomes, which were categorized by domain (Figure 2): caregiver burden (n=3), grief (n=1), treatment preference (n=1), resource utilization (n=2), patient’s dependence on caregiver (n=1), reaction to patient behavior (n=1), and shared activities (n=1). Among caregiver burden COAs, physical, social, and emotional domains were measured by all. Financial burden, worry, and work were also frequently assessed. Caregiving time was assessed by additional COAs.

Figure 1

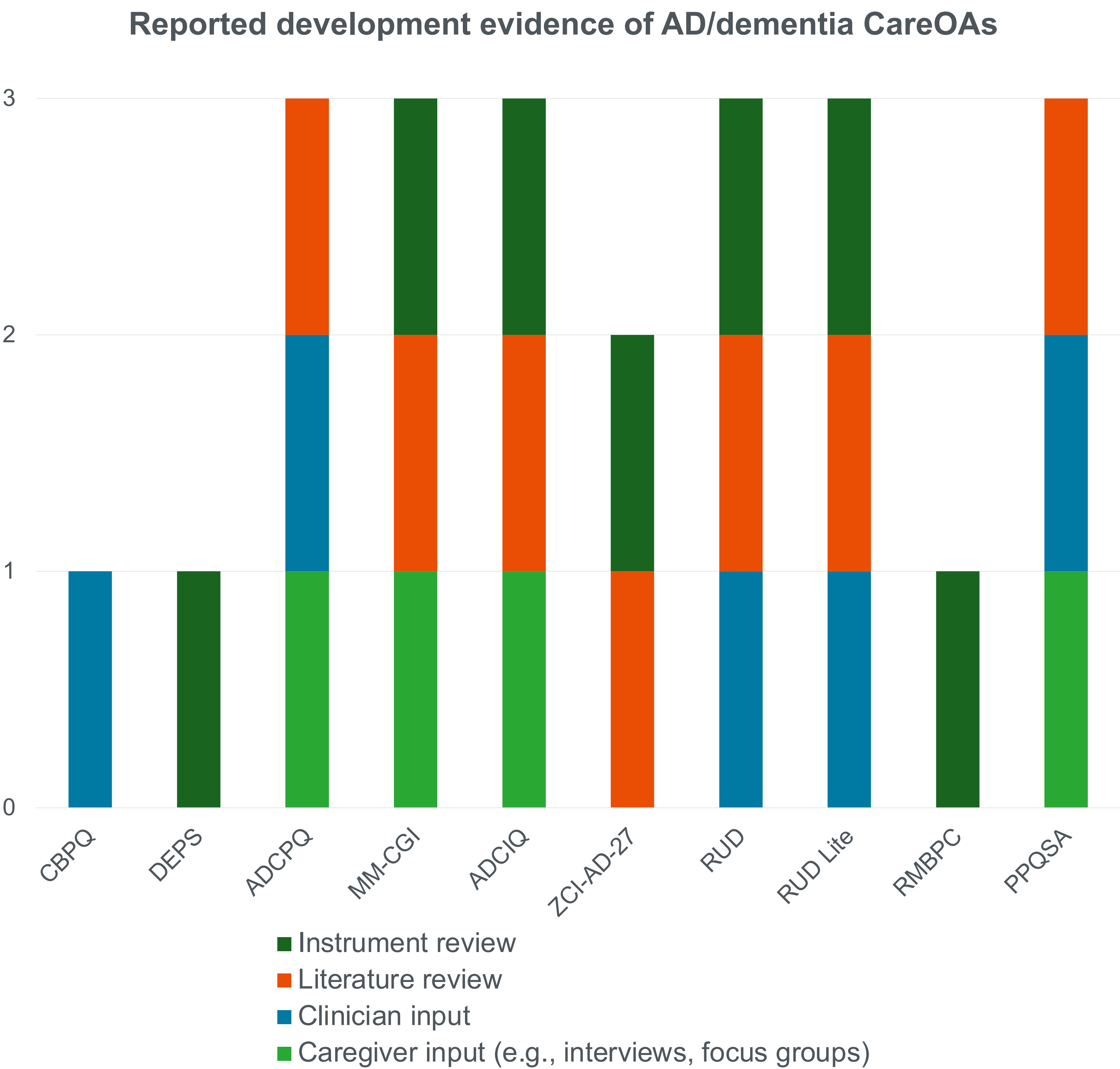
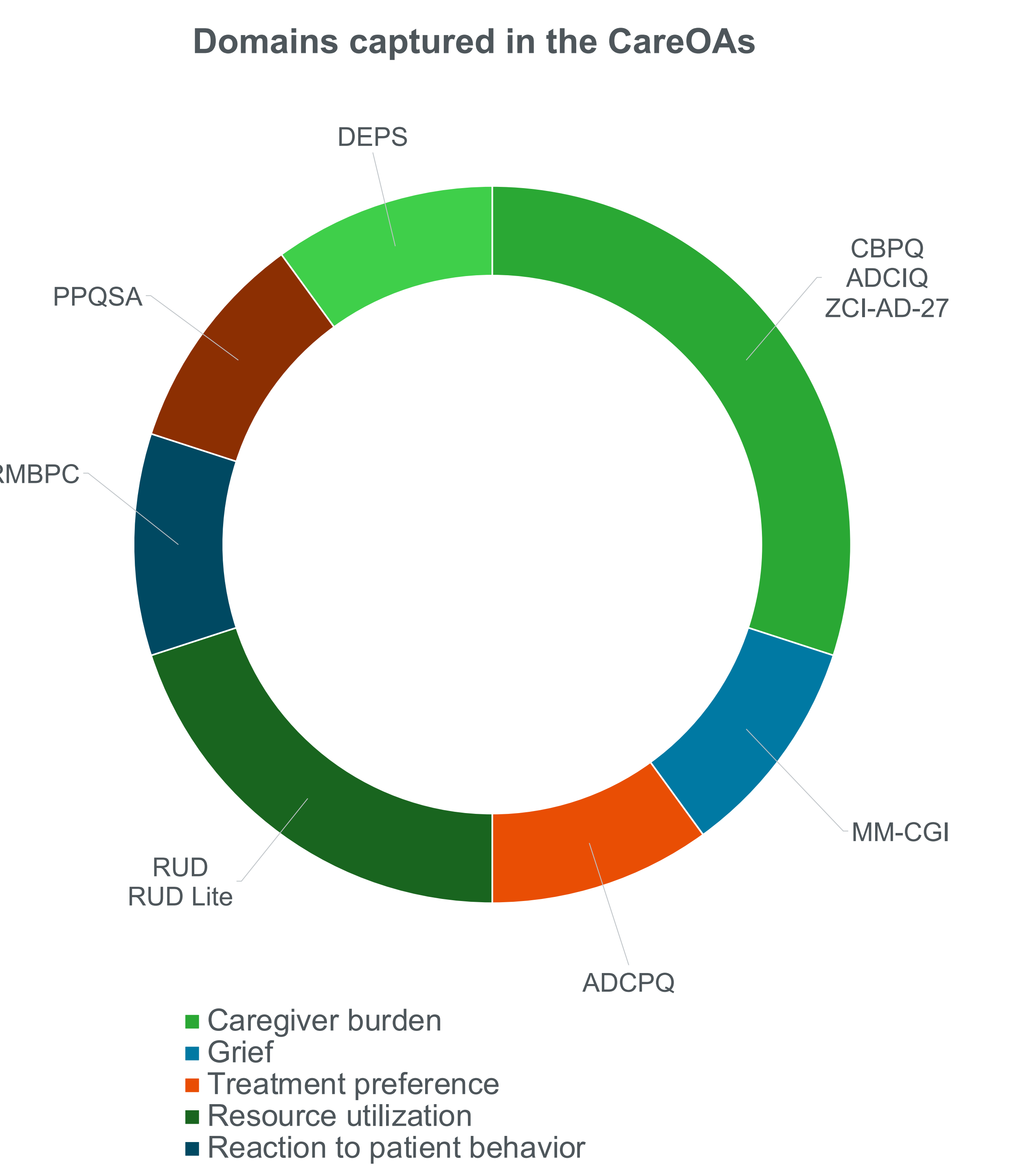


Figure 2



Conclusions

- While there are comprehensive and robust caregiver assessment options, they have varied content and response options. A future consensus should be made to inform the appropriate selection of CareOA content and response options in AD trials.

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