

The Socio-Economic Burden On Caregivers Of Pediatric Autistic Population In Europe: A Systematic Review

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Background

- Children with Autism Spectrum Disorder (ASD) often exhibit social difficulties, communication challenges, repetitive behaviors and restricted interests.
- Families of children with ASD are often burdened with their care, which may negatively impact their physical, psychological and financial well-being.

Objective

- To assess the social and economic burden on the caregivers of children with ASD in Europe.

Methods

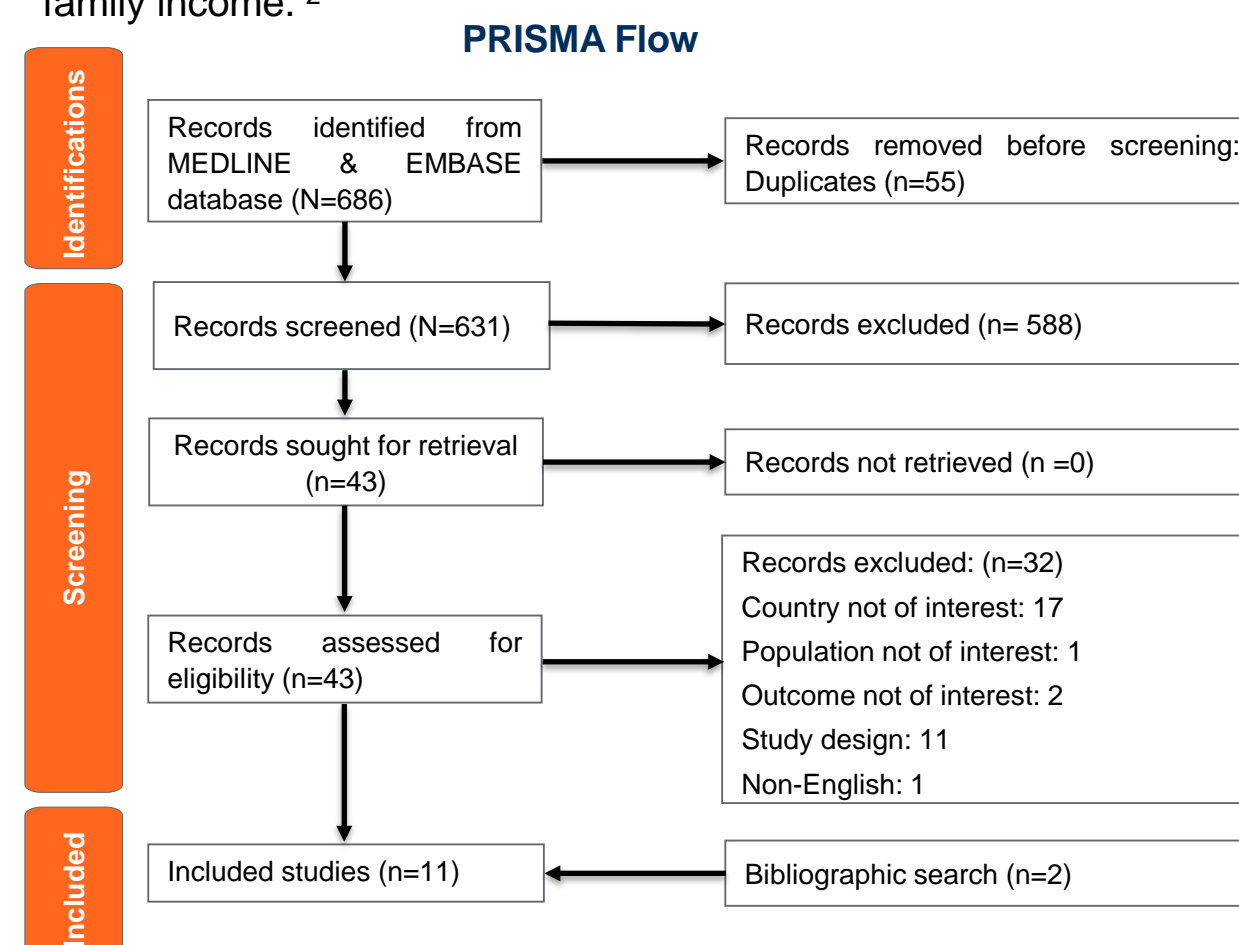
- A comprehensive literature search was conducted using Embase® and PubMed database. The literature was further supplemented using bibliographic searches
- The retrieval of articles was limited to caregivers of ASD pediatric patients covering their social and economic burden.

Results

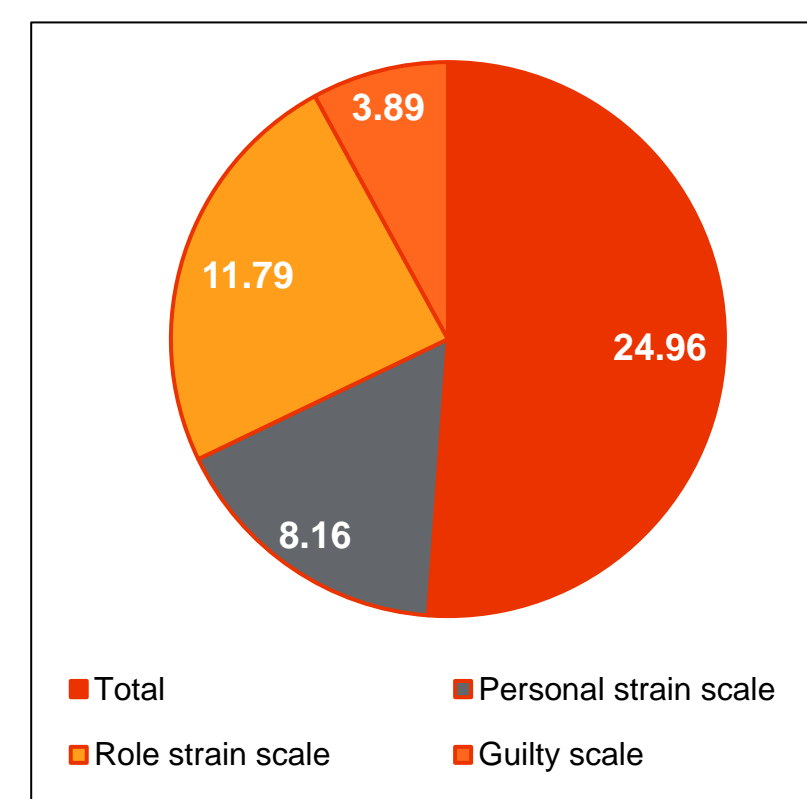
- Overall, 686 citations were identified through database searches. After screening articles based on their title and abstract, 43 citations were evaluated for their full-texts.
- Following detailed examination 11 studies were included. Additional 2 citations were included from the desk search.
- Different dimensions of caregiver burden were assessed using various scales:
 - Carer-related quality of life (Carer-QoL)
 - Role of the Father questionnaire⁴
 - Parent's QoL
 - Caregiver burden inventory
- The most frequent problems reported by primary caregivers while caring for children with ASD were relational (84%), physical (51%) and mental (46%) as per CarerQoL.^{1, 6}
- Paternal anxiety, depression and social isolation were the major co-variables that overburdened the carers and negatively impacted their QoL.⁴
- Mothers with ASD children had more frequent reduction in their working hours as compared with fathers (11% vs 79% $p < 0.001$).⁷
- Parents were found to bear 67% of the total societal costs, with annual mean out-of-pocket (OOP) expenditure being €9,489.60 per-family, which varied as per disease severity.⁸

- Families with children of level 2 and 3 ASD severity had €3,100.48 and €4,396.64 more OOP expenditure, respectively, than families of children with level 1 severity.⁸

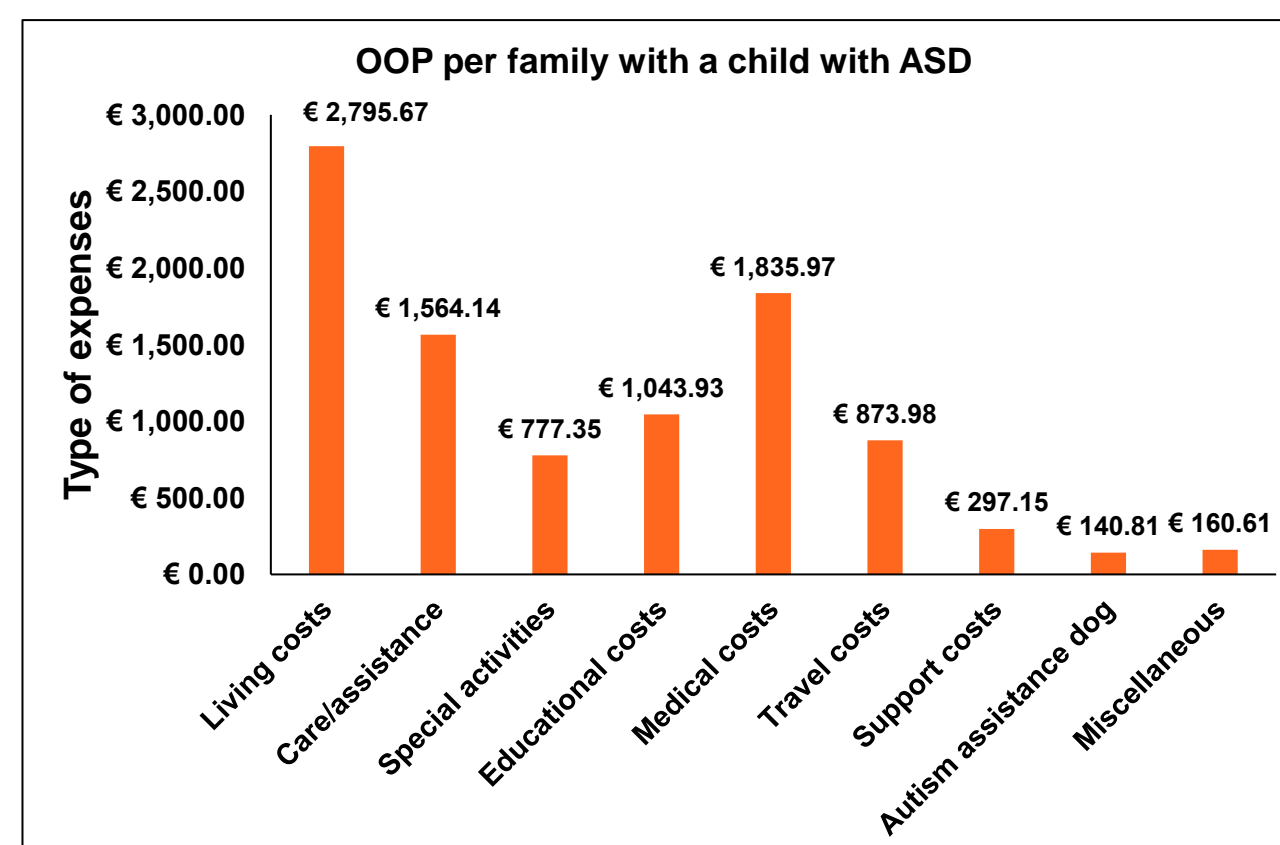
- COVID-19 restrictions further exacerbated the caregiver burden due to lack of professional intervention and reduced family income.²



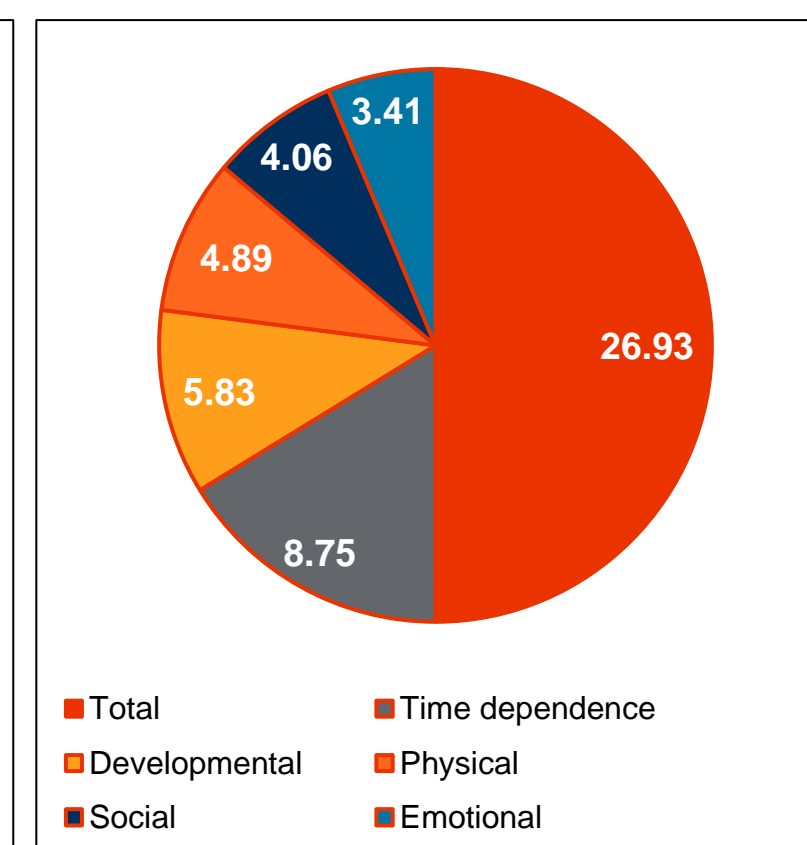
% Total scores of Zarit caregiver burden scale³



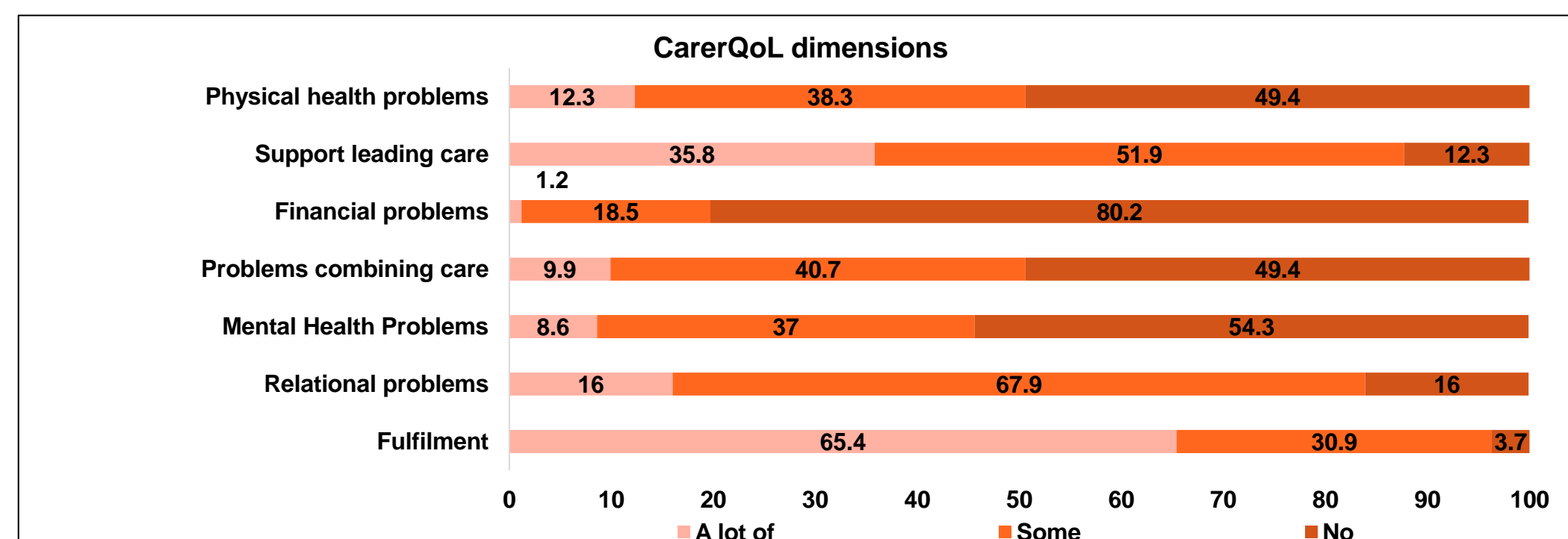
Out-of-Pocket expenditure (OOP) reported per family due to a child with ASD⁸



% Total scores of Zarit caregiver burden scale³



Distribution of CarerQoL reports among primary caregivers⁶



Conclusion

- High levels of stress and increased ASD severity among children were major variables that intensified socio-economic burden on caregivers.
- Thus, there is an urgent need for comprehensive support systems to address the multifaceted challenges encountered by caregivers of children with ASD.
- Furthermore, policies should be implemented to ensure equitable access to healthcare services, so as to minimize the financial strain on families having children with ASD.

References:

1.. Hoopen et al. 2022, Journal of Autism and developmental disorders, 2. Weyland et al. 2022, PloS ONE, 3. Purpura et al. 2021, Brain Sciences, 4. Rudelli et al. 2021, Research in Autism Spectrum disorders 5. Bieleninik et al. 2021, Brain Sciences, 6. Hoopen et al. 2020, Journal of Autism and developmental disorders, 7. Foody et al. 2014, Journal of Autism and developmental disorders, 8. Roddy et al. 2019, Autism, 9. Nawalana et al. 2020, International Journal of Developmental disabilities